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**A mixed methods study exploring organisational factors influencing the
development of services for people with dementia in English hospices**

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Abstract

Hospices are being challenged by changing demographics in the UK population. Originating from a response to cancer, hospices have struggled to diversify. As the population ages, dementia creates a particular challenge. A report by the Alzheimer's Society predicts that one in three of us will die with or from it (Alzheimer's Society, n.d. i) making it difficult to see how hospices can avoid adapting their organisations to respond in some way. This research aims to understand hospices from an organisational perspective, considering what might be maintaining hospices in their current form and how they are responding to the changing environment in the context of dementia. The study hopes to contribute to discourse and knowledge around hospices as organisations and the use of institutional theory in practice.

This mixed-method study takes an organisational perspective considering the hospice movement's response to dementia and introduces theories such as organisational institutionalism and institutional work theory. The research provides a historical and interpretive analysis of the topic including a variety of literature and fieldwork collected from a survey, interviews and a focus group. The study highlights challenges of institutionalism such as legitimacy and how this impacts institutional change. Fieldwork indicated, despite significant barriers there was a real desire to support people with dementia. The study offers two models of institutionalism that might shed light on the challenges of change within the movement. The research concludes that despite some individual efforts, there is no viable model or coordinated attempt to shift the narrative of hospice care away from cancer towards dementia. The research offers some recommendations for consideration if the hospice movement wishes to respond to this population.

Table of contents

Acknowledgements	I
Abstract.....	II
Table of contents	III
Glossary.....	VIII
Figures, tables and appendices.....	IX
Figures	IX
Tables	X
Appendices	XI
1 Chapter One – Hospice Care: growing pressures and demands for change	1
1.1 Why this topic – a personal perspective	1
1.2 Introduction to the challenge of hospice care for people with dementia ..	5
1.3 Research questions	9
1.4 How the external environment is changing and why there is pressure to change	10
1.5 How this research contributes to the knowledge base of hospices	13
1.6 Essential palliative care definitions to frame this research.....	16
1.7 Structure of thesis	21
2 Chapter Two – The theoretical lens of organisational institutionalism..	24
2.1 Part One - organisational institutionalism definitions	25
2.2 Part Two – discussion of organisational institutionalist theory, institutional work and associated concepts.....	31
2.2.1 Legitimacy.....	38
2.2.2 Agency.....	41

IV		
2.2.3	Institutional work theory.....	43
2.2.4	Maintaining and disrupting institutions.....	45
2.2.5	Institutional change	49
2.2.6	Decoupling	52
2.3	An organisational institutionalist perspective on the formation of the hospice movement	53
3	Chapter Three - review of the literature	60
3.1	Literature review search criteria	60
3.1	Literature search strategy.....	63
3.1.1	Historical literature	63
3.1.2	The relevance of hospice care for people with dementia	65
3.1.3	Policy literature	66
3.1.4	Empirical literature	68
3.2	The historical context	70
3.2.1	Care of the dying.....	71
3.2.2	Dementia	72
3.2.3	Cancer	74
3.2.4	The creation of the hospice movement.....	76
3.2.5	Dame Cicely Saunders and St Christopher's Hospice	78
3.2.6	The modern hospice movement.....	80
3.2.7	Hospice care today	83
3.3	The relevance of hospice care for people with dementia.	86
3.4	Policy literature related to dementia care at end-of-life	89
3.4.1	Part one - 2007-2011	90
3.4.2	Part two - 2012 onwards	96

3.5	Empirical literature in relation to hospice organisational literature	102
4	Chapter Four – methods and process	117
4.1	Research questions and objectives	117
4.2	Paradigm worldview	120
4.3	Theoretical lens.....	124
4.4	Methodological approach	128
4.5	Methods	129
4.5.1	Research design	129
4.5.2	Levels of the application of organisational institutionalism and institutional work theory within the research design	132
4.5.3	Chronological stages of the research	134
4.5.3.1	Ethical approval.....	134
4.5.3.2	Literature search	135
4.5.3.3	Recruitment of participants	136
4.5.3.4	Data collection	138
4.5.3.5	Analysis.....	141
4.5.3.6	Coding	143
5	Chapter Five - data collection results	146
5.1	Survey.....	146
5.1.1	Quantitative survey results	147
5.1.2	Survey Results as charts.....	147
5.1.3	Content Analysis	153
5.2	Focus group	154
5.3	Interviews.....	155

VI		
5.4	Themes.....	157
6	Chapter Six – organisational institutionalism - field level discussion..	159
6.1	Organisational field	160
6.1.1	History and the hospice movement	160
6.1.2	Hospice UK and legitimating actions	165
6.1.3	The sociological jolt of dementia	168
6.1.4	New and old institutionalism and barriers	169
6.1.5	Equity.....	170
6.1.6	Models of care	173
6.1.7	Workforce	176
6.1.8	Legitimacy.....	181
6.1.9	The institutional nature of hospice care	186
6.1.10	Decoupling.....	187
7	Chapter Seven – organisational institutionalism; institutional work and change	191
7.1	Section one: institutional work – agency in maintaining or disrupting hospice care.....	191
7.1.1	Evidence of disrupting acts of institutional work	191
7.2	Section two: institutional change	198
8	Chapter Eight – Conclusions.....	209
8.1	Addressing research question 1	209
8.2	Addressing research question two	215
8.3	Limitations.....	219
8.4	Summary.....	221
8.5	Recommendations	223

VII		
8.6	Final Reflections.....	225
9	References.....	227
10	Appendix One – literature search	237
10.1	Appendix 1A Policy Literature	238
10.2	Appendix 1 B - Literature relating to the applicability of dementia.....	241
10.3	Appendix 1 C – Empirical Literature	244
11	Appendix Two – ethical approval.....	249
11.1	Ethical Approval	250
11.2	Examples of consent paperwork	254
11.2.1	Interview consent form	254
11.2.2	Interview participant information.....	256
11.2.3	Interview sample questions	257
11.2.4	Focus group consent form.....	258
11.2.5	Focus group sample questions.....	260
11.2.6	Focus group participant information	261
11.2.7	Survey participant information	264
11.2.8	Sample Survey.....	265
12	Appendix Three – thematic map (see Chapter Four).....	267

VIII

Glossary

CQC	Care Quality Commission
DOH	Department of Health
GMC	General Medical Council
HUK	Hospice UK (previously known as Help the Hospices)
NCPC	National Council for Palliative Care
NICE	National Institute of Clinical Excellence
NHS	National Health Service
WHO	World Health Organisation

Figures, tables and appendices

Figures

1.1	Map of hospice organisational partners and or stakeholders and the locus of the research study	Page 9
1.2	The cancer dominance of specialist palliative care – data taken from minimum dataset report, (NCPC, 2016)	Page 13
2.1	Stage of institutional change (Greenwood, et al., 2002, p. 60)	Page 50
2.2	Institutionalisation and Institutional Change: Processes from a Dialectical Perspective (Seo & Creed, 2002, p. 225)	Page 51
4.1	High level, sequential mixed methods design	Page 131
4.2	Research design path	Page 131
4.3	Multi-directional influence of institutional work	Page 133
5.1	Was your hospice founded specifically to care for people with cancer or for a wider range of diseases?	Page 147
5.2	Does your hospice provide care for people with a primary or secondary diagnosis of dementia?	Page 148
5.3	If YES to question 5 (figure 5.4), for how long has your hospice provided services for people with dementia?	Page 149
5.4	Does your hospice have plans to increase services for people with dementia?	Page 149
5.5	Do you think that hospices have a role in supporting people with dementia?	Page 150
5.6	In considering your response to hospice care for people with dementia has this started with...?	Page 151
5.7	What are the barriers to providing hospice services for people with dementia?	Page 152

5.8	Are you being asked by commissioners to provide services for people with dementia?	Page 152
6.1	A hospice model of legitimacy	Page 182
6.2	The evolution and current structure of hospice as an institution (Hodges & Read, 2018)	Page 188
7.1	Stages of institutional change (Greenwood, et al., 2002, p. 60)	Page 198
8.1	The evolution and current structure of hospice as an institution (Hodges & Read, 2018, p. 771)	Page 217

Tables

1.1	Structure of thesis	Page 22
2.1	Old and new institutional thinking (Powell & DiMaggio, 1991, p. 13)	Page 35
3.1	Research topic – hospice services for people with dementia an ECLIPSE approach	Page 62
3.2	Search results for the relevance of hospice care for people with dementia	Page 66
3.3	Search results for policy literature	Page 67
3.4	Search results for empirical literature relating to hospices as organisations	Page 70
3.5	Hospice care today in numbers	Page 83
4.1	Research questions in relation to methods	Page 118
4.2	Key research design decisions	Page 130
5.1	Breakdown of survey response	Page 146
5.2	Themes	Page 157

Appendices

1. Literature search

- a. Policy Literature
- b. Applicability of palliative care for people with dementia
- c. Empirical search

2. Ethical Approval

- a. Letter of approval
- b. Amendment to include focus group
- c. Samples of ethics papers work:
 - i. Interview consent form
 - ii. Interview participant information
 - iii. Interview sample questions
 - iv. Focus group consent form
 - v. Focus group sample questions
 - vi. Focus group participant information
 - vii. Survey participant information
 - viii. Example survey

2. Thematic map

1 Chapter One – Hospice Care: growing pressures and demands for change

1.1 Why this topic – a personal perspective

This section sets out why this topic was chosen and how I connect with it both as a practitioner and as a researcher. Therefore I have written this section in the first person and thereafter will revert to the third person.

My professional background is in Human Resources (HR). Prior to joining my employing hospice, I had worked as an Assistant Director of HR, focusing on workforce redesign and development for a large acute hospital. My area of interest within HR has always been organisational development and issues related to culture and change.

My Master's Degree in Regeneration included an eclectic mix of modules. In collaboration with three universities I participated in the design of one of the modules which concentrated on transformation and change within a healthcare setting. The module aimed to support healthcare managers at the acute trust, feel better prepared for the transformational changes required, in meeting the challenges of a redesigned health economy and to address financial deficits. The module introduced me to organisational cultural mapping tools. In fact, in the pilot for my professional doctorate, I used a focus group to think about whether the cultural web (Johnson, 1990) or Edgar Schein's 'three levels of culture' (which analyses artefacts, espoused beliefs and values and basic underlying assumptions (Schein, 2010)) helped to better understand the issues around hospices providing services for people with dementia. I have an interest in how these stories and beliefs impact organisational behaviour and influence change.

An additional module was Empowering Communities which examined issues of community participation, welfare dependency and deprivation. My work involved working with North Staffordshire Regeneration Zone, Stoke-on-Trent College and

the Job Centre, relating to supporting people who were long-term unemployed to return to work and this stimulated my interest in issues relating to social deprivation and inequality.

These two areas of concern (i.e. organisational development and inequality) integrated professionally in my role in the NHS and at the employing hospice; firstly the interest in workforce, organisational and service design and secondly issues relating to inequality. The influence of these modules, combined with my HR experience contributed to researching further into organisational behaviour and my choice of organisational institutionalism as the theory for this thesis. I discuss the theory in more detail in Chapter Two as it provided a lens through which to look at issues relating to organisational culture, decision making and change, and how they may help hospices understand their continued dominance of cancer in their care services.

When dementia became UK headline news in 2012 (Cameron, 2012), I had been at the employing hospice nearly three years as Business Support Director and later Deputy Chief Executive. In response to the challenge to hospices that was a part of the framing of the issue of dementia, I scheduled a meeting to understand how we were developing our services to meet this new and growing demand. It came as a surprise that we'd not really considered hospice care for this group of people. There were some major concerns expressed relating to the differences in the needs of dementia patients compared to patients the team were confident in caring for. During these discussions I began to contemplate how the history of hospice care was dictating and informing its current strategy.

My prior involvement with hospices had been in relation to the employing hospice caring for my Dad at the end of his life, he had kidney cancer. I did not know that hospice history was so steeped in the provision of care for people with cancer or the journey to 'specialisation' (Clark, 2016 i). I had not been institutionalised, i.e. the way I framed or made sense of the organisation not being steeped in the

norms of its culture, history or narrative. I did not at this point appreciate the significant challenges that might face hospice workforces or hospice organisations in caring for people with dementia.

The employing hospice became involved in a few specific dementia projects from 2013, which included a two-year pilot service with primary care partners supporting early diagnosis; increasing awareness as part of the national Dementia Friends initiative (Alzheimer's Society, n.d. ii); and hosting a 'dementia debate' internally to sound out views from teams. The primary care services operated on the fringes of the hospice, it impacted none of the existing core hospice teams and therefore did not disrupt or challenge the norms of their practice.

I presented at a Hospice UK Conference in March 2015 following the publication of Hospice Enabled Dementia Care (Hospice UK, 2015). It was during this time that I became aware of the organisational and cultural change required to support people with dementia and from where this research topic developed.

In October 2015 I became CEO at the employing hospice and the Chair of Trustees asked me to produce a new five-year strategy which developed alongside a review of our brand. Becoming CEO had more of an impact than I'd expected, my natural drive for issues of equality of access became increasingly combined with financial sustainability and managing demand. Due to the financial constraints of hospices and the local health economy, 'Who can we afford to care for?' became a significant issue for me in planning our new strategy. The 'who' we care for is entwined with issues of organisational culture as are questions relating to 'what we are' and how staff and volunteers make sense of our identity.

Alongside this work on strategy, I also started to build connections with an international charity providing services for people with dementia including at end of life. Being part of conversations, visiting services, hearing about the

challenges facing people with dementia cemented my passion about this issue. I became increasingly frustrated that there did not appear to be sufficient movement towards a solution for this group of people.

In addressing these issues for our strategy, definitions became important, or at least creating an accepted understanding of these definitions for the employing hospice and our community (Section 1.6). We needed to decide to what extent the hospice was (or continued to be) a specialist palliative care provider. If so, whether we had a role in supporting people without complex care needs or with a palliative disease like dementia. An overview of hospice services is provided in Section 3.2.7.

During this time, my research and my role influenced each other, my reading relating to definitions of end-of-life care shaped and informed how I made sense of the challenges within our strategy. The predicted prevalence of dementia, meant that it was impossible to consider our strategy, without addressing this demographic.

I did eventually (through consultation, research, reading and reflection), determine a service model for the employing hospice which to an extent includes dementia, and we agreed a way forward that addressed the questions above. I presented this model as part of a Hospice UK conference session on 'Frailty, whose role is it anyway?' (Hodges, 2017). I would say we are now at the beginning of a journey of change, and that many of the norms and values of our teams will be challenged by the strategic direction agreed by our senior management team and Trustee Board, in consultation with the wider team and stakeholders.

This section has focused on my personal reasons for the choice of research topic, connecting my professional background in HR with my role as a hospice Chief Executive. The next section which reverts to the third person, will provide background to the environment within which I locate this research.

1.2 Introduction to the challenge of hospice care for people with dementia

Originating out of a response to the needs of people with cancer just over fifty years ago, the United Kingdom (UK) hospice movement is at a crossroads. Just as cancer replaced tuberculosis as the leading cause of death (Rossi, 2009), dementia has now taken its place. It is predicted that one in three of us will die with or from it (Alzheimer's Society, n.d. i).

Dementia UK define dementia as 'an umbrella term used to describe a range of progressive neurological disorders, that is, conditions affecting the brain...There are many different types of dementia, of which Alzheimer's disease is the most common' (Dementia UK, n.d.). Dementia is also now widely recognised as a palliative condition (Section 3.3) and therefore arguably within the realm of hospice care.

Over two hundred independent organisations, predominately charities make up the hospice movement. The term 'movement' is used throughout the thesis to describe the population of hospices, the particular significance of the term is discussed in Chapter Two, Section 2.1. However, hospices are not a homogeneous group; whilst there is a basic similarity of purpose, constitution, legal form, and identity there are many sizes of hospices, with a variety of service offerings and different organisational challenges. Hospices are supported and often represented nationally, by a membership organisation, Hospice UK (www.hospiceuk.org). Collectively, hospices care for over 200,000 people per year with eighty percent of care provided out in the community (Hospice UK, 2016, p. 2). Most of the funding spent on hospice care is raised via voluntary sources, on aggregate, £2.7 million must be raised every day (Hospice UK, 2016, p. 5). The ability of hospices to generate such significant local support is evidence of the place they hold in the hearts of their communities. The UK hospice movement leads the way internationally and is heralded as part of the

reason the UK ranks first in the 2015 Quality of Death Index (The Economist, 2015). Hospices provide excellent care, 'outstripping the performance of any other sector' (Care Quality Commission, 2018, p. 4).

However, the population is changing, with cancer increasingly seen as a long-term condition with increased survivorship (NHS England, 2015). The growing number of frail older people with multiple health conditions, frailty and dementia is impacting on health services, including hospices. As a result, this changing demographic is challenging the identity and culture of hospices and might impact the generosity of the local population. Peter Holliday, a previous hospice Chief Executive, believed that 'in the second half of the twentieth century, communities supported hospices because of their fear of cancer but in the first half of the twenty-first century it is a fear of dementia which will drive the direction of community support' (Holliday, 2014).

Hospices, individually and collectively, need to determine how they will respond to the changing environment. This thesis specifically focuses on the question of hospice care for people with dementia, recognising that this is not a simple distinction, people dying with multiple diseases is significant. Dementia has caused debate within the hospice movement as to the most appropriate way to meet this population's needs and the impact this may have on existing services (Hospice UK, 2015). Relevant to the debate is how physical health and mental health have been separated within the statutory provision and the readiness therefore, of a movement grown out of care for a physical disease, to translate that care for a disease considered being primarily the realm of mental health.

The quandary that the challenges of dementia creates for hospices, combines the functional nature of the organisation (i.e. finance and resources) with wider factors related to culture and identity, i.e. to what extent is the hospice movement defined by its history, and therefore cancer. The functional challenges are significant. The question of funding is a key determinant of the ability for

hospices to do more. In 2017, 45% of hospices recorded financial deficits with 34% seeing a reduction in reserves levels (Hospice UK, 2018, p. 27).

There is a choice of lenses through which to view this dilemma, for example, a clinical lens could review practical models of service delivery or a resource mobilisation perspective could deliberate over the economic factors such as capacity and funding. However, given the combination of functional and cultural issues, these lenses might not be sufficient in considering factors such as the social context within which hospices operate, their culture, identity, norms/values. These factors are key to understanding how hospices respond to external challenges such as dementia as they provide insight into how an organisation thinks and behaves. Whilst not ignoring these functional challenges, this research is focusing on exploring the wider factors related to history, culture and identity.

Initially consideration should be given to addressing the perceived aversion many professional people working in hospices may have to the word 'institution'. For hospices and many healthcare practitioners, the term 'institution' has a negative connotation, associated with workhouses and large inpatient settings where being 'institutionalised' was a negative outcome for residents (Goffman, 1961, reprinted 2017). There is literature which suggests that palliative care is institutionalised (in the form described by Goffman, 1961) and that this model of care is devaluing the patient and their condition (Sinclair, 2007). Whilst it should be considered in any discussion regarding models of care for people with dementia, the connections between service delivery and institutionalised care, whilst an important area of study, sits outside of this research.

The term needs to be re-framed and understood from the perspective of organisational theory so that healthcare practitioners can adopt it to help better understand the social context within an organisation. To suggest that the 'hospice movement' is institutionalised, may appear to some as a descriptor of the type of care rather than as used in this thesis, term used in organisational

theory. This research is focusing on institution as a definition relating to organisations, and specifically, the ways in which the social context within and outside an organisation shape the character of the organisation.

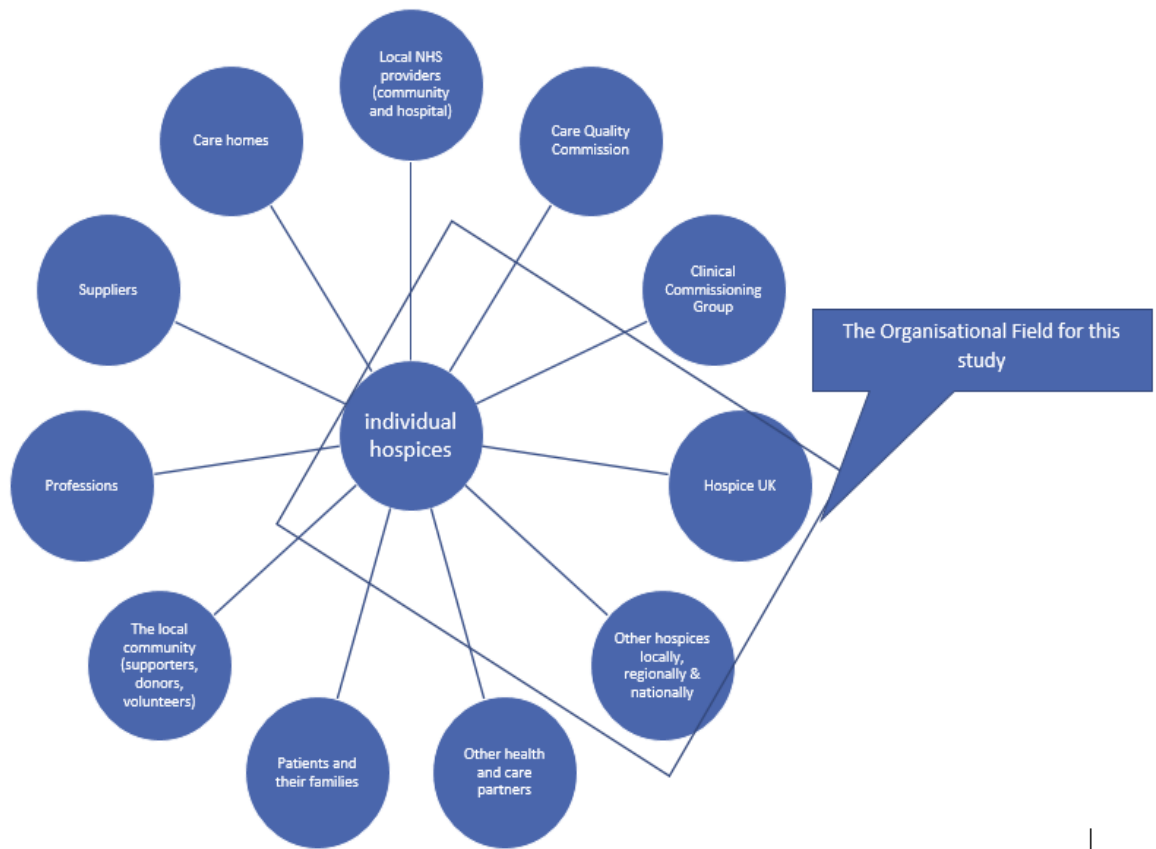
Organisational institutionalism is explored in Chapter Two. In summary, this approach considers how the institutional context 'i.e. widespread social understandings' (Greenwood, et al., 2008, p. 3) can impact how organisations, and individuals within them, behave. Whilst all organisations can be subject to being influenced by their institutional context, not-for-profit organisations (such as UK charitable hospices) are considered particularly sensitive (Greenwood, et al., 2008). Greenwood et al. (2008) suggests that this might relate to the technical outputs of the organisation being harder to quantify. It may also be because of the reliance on, and commitment to, their role in the local community to generate income, for their distinctive contributions to social life and hence their legitimacy.

Aims

The primary aim of this thesis is to understand the extent to which the institutional context of hospices may impact the development of services for people with dementia. For example, is the social understanding of the hospice movement being so aligned to cancer part of a perceived resistance to change?

Hospices work alongside a range of other organisations and groups as depicted in Figure 1.1. This study could have considered the views of other stakeholders within the field of palliative care. However, to understand the issues as constructed within the hospice movement, the locus of the study was the organisational field (see Section 2.1) of hospice care i.e. individual hospices and Hospice UK.

Figure 1.1 - Map of hospice organisational partners and or stakeholder and the locus of the research study



1.3 Research questions

This section details the research questions. The study is broken down into two key questions and five sub-questions:-

Key question one - To what extent does the history, culture and identity of the hospice movement support or inhibit responses by hospices to the pressure (in policy, demographic changes and public expectation) of developing services for people with dementia?

- i. How are hospices defined?
- ii. How is the 'field' of hospice care (hospices collectively) defined and organised?

- iii. How are hospices, individually and as a 'field' reading and responding to internal and external pressures to develop services for people with dementia
- iv. What is the role of Hospice UK (the movement's membership organisation) in influencing hospices on the topic of dementia?
- v. How have hospices engaged with the dilemma of services for people with dementia and what are the associated barriers?

Key question two - Given this exploration of these organisational factors, what are the prospects for a (collective) response by hospices to the challenges posed by the demographic changes being faced?

This section has introduced the context and focus for this research study, section 1.4 will explore the contemporary changing environment that shows why research on this topic applies and is important.

1.4 How the external environment is changing and why there is pressure to change

The UK population is changing, and this is impacting the demand for hospice care. In 2012, deaths in England and Wales increased, with predictions of a rise from approximately 500,000 people dying annually to 590,000 by 2030 (Leadbeater & Garber, 2010). The UK population is ageing and, it is predicted that by 2035 almost half of people dying will be 85 years old or over (Calanzani, et al., 2013). Dementia in the UK is predicted to increase from 850,000 in 2015 to over 2 million by 2051 (Alzheimer's Society, n.d. i).

Hospices provide care for people who are living with a palliative disease (Section 1.6, definitions), who are dying and for people who are bereaved, therefore more people dying, has significant implications for hospices. There is evidence of a rising expectation that hospices should meet some of this need (Hospice UK, 2013, 2017; Leadbeater and Garber, 2010).

Hospice UK, reported in 2017 that one in four people who need hospice care cannot access it (Hospice UK, 2017 ii), and highlighted the scale of challenge for hospices if expected to meet this need. Hospice UK has also provided a steer to the movement on how it might widen access beyond cancer, through publications such as *Hospice Enabled Dementia* (2015) and *Heart Failure and Hospice Care* (2017 ii). These publications acknowledge the growing call for hospices to further increase access to hospice care beyond cancer (Leadbeater and Garber, 2010, Hospice UK, 2013; Marie Curie & Alzheimer's Society, 2015; and Hospice UK, 2015; Hospice UK, 2017 i).

Views from members of the public during the Commission into the Future of Hospice Care (Hospice UK, 2013) included 'If you don't have cancer, you're almost treated as a second-class citizen' (Help the Hospices, 2013, p. 17) and in relation to dementia the Commission 'heard a passionate and convincing call for the engagement of hospices in end-of-life care for people with this condition given its high symptom and disability burdens and the challenges faced by carers' (Help the Hospices, 2013, p. 17).

There are many challenges facing hospices, for example lack of financial resources from both statutory and voluntary sources, the continual reorganisation of the NHS and concerns around future availability of both its paid and voluntary workforce. However, given the increasing prevalence of dementia within UK society this challenge cannot be ignored. It is highly likely that dementia will impact on resources, models of care and decision making as hospices are highly likely to be seeing staff, volunteers, family members and patients with dementia. As things stand, and because hospices are not fully funded by the NHS (charitable income funds the majority of care), NHS commissioners will not necessarily determine the organisational response at local or movement level. As Hospice UK do not have the ability to direct the movement, any response will ultimately be decided by individual management teams and trustees. However,

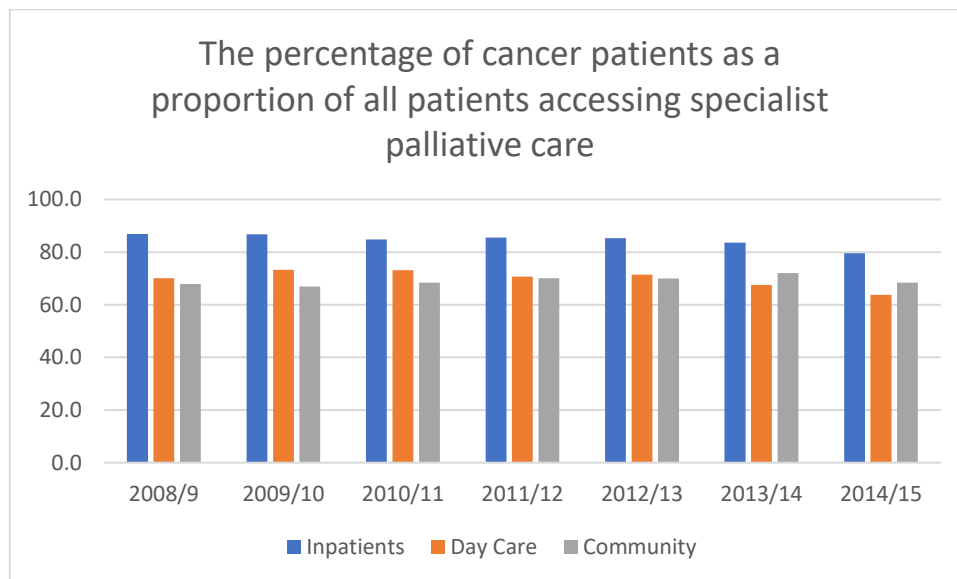
as part of an organisational field, hospices influence each other sharing and debating issues such as direction. It is possible that individual organisations respond very differently in their solutions to the challenge of dementia creating pressure to the stability of the field and overall direction of the future of the hospice movement.

Pressures for hospices to change are coming via external sources such as the changing demographics and variety of policy documents on the subject (see Section 3.1.3) and from within the movement itself. Some of these internal challenges to change come not only from Hospice UK but also from individuals who have views on the future direction and identity of hospice care, and in this thesis, in relation to dementia. The extent to which individuals are influencing the development of hospice services for people with dementia, for and against, is a key focus of this thesis and is discussed throughout.

Despite these challenges having not appeared overnight, hospices have operated services for a broadly similar disease group for fifty years. There is evidence that hospices have innovated around the boundaries resulting in a range of services for people who have a non-malignant disease. For example, St Richard's Hospice in Worcestershire and St Christopher's in London (Wilderspin et al., 2017, Hospice UK, 2017 i). However, data shows that specialist palliative care (Section 1.6, definitions) for people with cancer, still dominates hospice care (Hospice UK, 2017 ii).

Figure 1.2 is based on data taken from the National Council for Palliative Care's Minimum Data Set (2016) which was published annually. The graph shows the number of people with cancer as a proportion of all patients accessing specialist palliative care. This dataset is not complete and includes NHS services not just hospice care. However, it shows that the high proportion of cancer patients has not significantly changed over this seven-year period, later data is not available (The National Council for Palliative Care, 2016).

Figure 1.2: the cancer dominance of specialist palliative care – data taken from the minimum dataset report, NCPC (2016)



This section has focused on why the question about whether care for people with dementia can, and should, be provided by hospices is of relevance. Section 1.5 will discuss the specific contribution this research aims to make.

1.5 How this research contributes to the knowledge base of hospices

Perhaps unsurprisingly, most research into, and used in, hospices comprises of clinical studies relevant to the provision of palliative care. There is little research into hospices as organisations. In trying to understand why hospices have remained dominated by care for people with cancer and why the emergence of dementia has presented such a challenge to the hospice movement, an organisational approach made sense. There are obvious (functional) constraints that mean a response is problematic, practically, such as finance, capacity and workforce resources, which have made business models and clinical models of the hospices that include dementia care seem risky. However, it has seemed, from discussions within the movement, that there is also something more deep-rooted, a resistance to or separation from the question of how provision is made for dementia care that is related to the history, culture and identity of hospices.

Understanding more about the organisational dynamics of hospice care, might, then, help the movement continue to develop and evolve, in such a complex landscape.

Whilst choosing to research this issue from an organisational perspective rather than a clinical perspective makes sense, organisational theory is incredibly broad. Searching for the most appropriate theoretical lens, to an extent depends on issues relating to personal epistemological and ontological perspectives which will be discussed further in Section 4.2.

As a way of understanding how organisations behave, organisational institutionalism combines a consideration of the functional nature of an organisation and the social context within which it operates. It accepts the nuances of human behaviour within a functional structure, how they perceive themselves, each other, their environment, and their roles. One of the founders of the institutional perspective, the sociologist Philip Selznick, describes an institution as a 'natural product of social needs and pressures – a responsive, adaptive organism' (Selznick, 1957, p. 5) and that 'taking account of both internal and external social forces, institutional studies emphasize the adaptive change and evolution of organisational forms and practices' (Selznick, 1957, p. 12).

Selznick describes the adaptation with 'new patterns emerging and old ones declining, not as a result of conscious design but as natural and largely unplanned adaptations to new situations' and goes on to say that 'the most interesting and perceptive analysis of this type show the organisation responding to a problem posed by its history' (Selznick, 1957, p. 12). Selznick's analysis has been developed in a variety of ways, (these discussed in Chapter Two), but his original statement suggests that the theory offers a useful and valid frame through which to examine the continuing story of hospice.

There is a new and emerging pattern evidencing that more people are dying with or from dementia than cancer. This is not a planned adaptation for hospices, this

is an external pressure due to a new situation because of a shift in the environment in which they operate. The development of services for people with dementia, is a problem posed by the hospice movement's history which is that of care for people with cancer. It should be highlighted that the majority of hospices were not developed solely for patients with cancer (Figure 5.3), therefore making it difficult to exclude a particular group.

Several strands of theory are introduced in Chapter Two such as institutional work, legitimacy and identity. An organisational institutionalist perspective, will add depth to the understanding of the hospice movement as a phenomenon that has grown outside of the NHS, to have distinctive standing, identity, significant social value and community support. The blend of organisational institutionalism and institutional work, enable consideration of individual acts that are maintaining or disrupting hospice organisations in addition to considering the movement in its entirety.

The significance of this study is that hospices urgently need to consider the contemporary challenges they are facing, and there are very few studies on UK charitable hospices as organisations. Dementia is arguably big enough in terms of prevalence to warrant the need to understand what drives hospices when making strategic decisions; how external and internal influencers impact future direction; the impact of being part of a national organisational field and the significance of hospices' history, identity and values when it comes to decision making and change. The demographic changes create the sort of 'precipitating jolt' i.e. an event that has the possibility of 'destabilising established practices' that can result in actions that aim to maintain or disrupt institutional norms (Greenwood, et al., 2002, p. 59). This study aims to contribute to knowledge in two fields: primarily to knowledge about the developing field of hospice care and, specifically, to understanding of issues relating to organisational change in the

hospice movement; and secondly, to the body of empirical work relating to organisational institutionalism and institutional work theory in the third sector.

This section has set out the contribution of this research. Section 1.6 will discuss clinical definitions that need to be understood in the context of this thesis. These definitions add to the understanding of organisational and professional identity, and are therefore central to issues relating to institutional change.

1.6 Essential palliative care definitions to frame this research

Before launching into a discussion on this topic, it is necessary to pause and describe some of the issues relating to definitions. In the context of this research these definitions are also a matter of organisational identity, and how members of hospices make sense of their professional roles, or their sense of belonging. The definitions are also important when illustrating how hospices are seen by other interlinking fields of practice such as the NHS, and in how hospices may decide who they care for and how.

Definitions in this field of clinical practice are confusing, with terms such as specialist palliative care, generalist palliative care and end-of-life care being used interchangeably. This confusion can act as a barrier to accessing care, integrating services and in clinical practice (Russell, 2015; Mitchell, 2016).

Particular confusion exists between the terms palliative care and end-of-life care. There are diseases (like dementia and multiple sclerosis) which can have a long trajectory, meaning that people can live with these illnesses for many years. These diseases currently have no cure and in that sense, are palliative and there is research that demonstrates the benefits to patients of accessing palliative care early (Ziegler, et al., 2017). Mitchell's view is that palliative care is applicable early in a disease trajectory, at the point when the disease is deemed incurable, with end-of-life care being associated with advanced disease where the patient is in the last twelve months of life and is therefore, a continuation of palliative care (Mitchell, 2016).

If hospices are 'palliative care charities', then diseases such as dementia are interesting in the context of these definitions. Hospices might be expected to provide services for many years rather than just the last twelve months and whether this is desirable or sustainable remains questionable. Equally if hospices are 'end-of-life care charities' that might suggest caring for people who are frail due to advanced age and do not have a 'palliative disease'. The issue of frailty and hospice care, whilst outside of the scope of this study, raises similar questions to those related to dementia. The question of 'who hospices care for' remains a common theme in much of the hospice discourse with no concrete agreement (Hospice UK, 2013; Hospice UK, 2017; Leadbeater and Garber, 2010).

There are a range of standard definitions which will now be discussed, following which, clarity will be provided as to which of these are adopted for the thesis.

The World Health Organisation's (WHO) current definition of palliative care (2015) is one of the most commonly, internationally used definitions of palliative care and states:

'Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual' (World Health Organisation, 2015).

This definition adopts a wide range of diseases, 'life-threatening' would include diseases with a longer trajectory; and it does not put a timescale on care.

The term 'end-of-life care' also has numerous definitions and therefore is not fully understood (Russell, 2015). The General Medical Council (GMC) provide guidance relating to the term 'approaching end-of-life' which is all inclusive and is defined as:

- 'advanced, progressive, incurable conditions,
 - general frailty and co-existing conditions that mean they are expected to die within 12 months,
 - existing conditions if they are at risk of dying from a sudden acute crisis in their condition
 - life-threatening acute conditions caused by sudden catastrophic events'
- (General Medical Council, 2010, p. 8).

This GMC definition does not use the phrase 'palliative care' at all, although the first category would be consistent with the WHO definition i.e. 'incurable conditions' being similar to 'life-threatening illnesses', however, the use of 'advanced, progressive' articulates that the disease has moved into a deteriorating phase. This is helpful as someone with dementia or MS may be in an early stage of their disease, it is still 'life threatening' and therefore 'palliative' but does not necessarily mean they are at the 'end-of-life' and they would therefore be outside of this GMC definition until their disease progressed.

The difference between palliative care that is 'specialist', in comparison to 'generalist' is significant in hospice narrative and issues of professionalisation and role identity. The term 'specialist' relates to professionals with recognised additional training. Palliative care became a medical specialty in 1987 (Clark, 2016 i) with hospices being commissioned to provide 'specialist palliative care'. Referral documentation includes questions about 'what specialist need' a potential patient has (Pan Birmingham Cancer Network, n.d.) .

Commissioning guidance produced collaboratively by a number of interested parties including the Association of Palliative Medicine, National Council for Palliative Care, Marie Curie Cancer Care and others (Association for Palliative Medicine, 2012) describes specialist palliative care as: 'the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative

care training. The aim of the care is to provide physical, psychological, social and spiritual support' (Tebbit, 1999 cited by Association for Palliative Medicine, 2012), p. 6).

This definition argues that specialist palliative care in comparison to generalist palliative care relates to the need for a team with additional skills. This suggests that there is some complexity, not just 'progressive, advanced disease'.

Hospice care is defined by Hospice UK as:

'Hospice care seeks to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal illness, helping them live as fully as they can for the precious time they have left. It aspires to be accessible to all who could benefit and reflect personal preferences and needs' (Hospice UK, n.d.)

The extended definition adds:

'hospices offer wide-ranging, personalised care which is provided by a versatile team of different professional staff and volunteers. As well as taking care of people's physical needs, they also look after their emotional, spiritual and social needs. They also support carers, family members and close friends, both during a person's illness and during bereavement. Hospice care is free for everyone, and is provided for however long it is needed, which could be days, weeks or even months' (Hospice UK, n.d.).

Hospice UK's definition does not use the terms 'palliative care, 'specialist' or 'expert' which have been included in previous definitions. Perhaps losing these terms is an attempt to reduce some confusion, however, 'life-limiting or terminal illness' would include a wide range of diseases including dementia and 'life limiting' is itself subjective. The 'accessible to all who could benefit' would surely

apply to those who are 'frail', however, it would be assumed that the 'all' is related to the 'life-limiting or terminal illness' which might exclude frailty. The extended definition talks about 'even' months which would suggest any extended support is less common. However, some terminal illnesses have a trajectory that can be many years which raises the question of when 'hospice care' is accessible. Any definition from Hospice UK aiming to reflect the narrative of hospice, their future strategy and views of their members is likely to be open to interpretation from its diverse membership base.

For the purposes of this thesis, the following definitions will be adopted: -

- **Palliative care** - the WHO definition of palliative care will be used. This is because it provides the widest range of disease trajectory i.e. anyone with a life limiting illness, and does not determine how long someone may live with the condition. In addition, the definition does not determine 'complexity' i.e. whether the need is 'specialist'. Therefore, the WHO definition embraces dementia.
- **Specialist palliative care** - the commissioning framework's definition of specialist palliative care will be adopted in the context of perceived complexity and the need for a team with specific expertise and training. This is due to it being an accepted definition by the hospice movement and NHS commissioners.
- **Generalist palliative care** – this phrase will relate to any palliative care that is not consistent with the 'specialist' definition above.
- **End-of-life care** – the GMC definition is broad, it uses 'advanced, progressive' to articulate that a life limiting condition is moving towards the point at which someone will die from it. Therefore, this definition will be used to identify people in the last stage of their life.
- **Hospice care** – for the purposes of this thesis the term 'hospice care' will relate to care provided by hospice organisations rather than a definition

of a category of care. Choosing an organisational definition provides breadth and recognises that hospices may provide slightly different services which span palliative and end-of-life care for those eligible for its services.

- **Hospice movement** – a descriptor for hospices organisations on aggregate. The historic and current relevance of the word ‘movement’ will be discussed in Section 2.3, and during some elements of the analysis.

Section 1.6 has attempted to provide an overview of the various clinical definitions that are key to this research topic, and to provide clarity on how these will be utilised within this thesis. It is recognised of course, that definitions or their interpretation, can change overtime which can alter the understanding of these terms.

1.7 Structure of thesis

Each chapter will deliberately end with a short reflection from the researcher written in the first person. This is to tell the story of the research and creation of this thesis and to provide insight on the many challenges faced. The overall structure is as follows:

Table 1.1 – Structure of thesis

Chapter Number	Description
Chapter Two	An overview of the theoretical framework focusing in particular, on organisational institutionalism and institutional work theory.
Chapter Three	Literature review including discussion focusing on background, policy and empirical studies relevant to this thesis.
Chapter Four	The research methods and processes implemented
Chapter Five	A summary of the results from the fieldwork
Chapter Six	Data findings presented within a discussion around organisational institutionalism
Chapter Seven	Data findings discussed in the context of institutional work and institutional change.
Chapter Eight	Final conclusions and recommendations

Chapter summary

Chapter One introduces the research topic, providing insight into the challenge faced by hospices, as they consider the impact of the ageing population and prevalence of dementia. It outlines both why this topic is of interest to the researcher and what knowledge the research hopes to contribute to hospices and institutional studies. The chapter discusses the variety of definitions that are used in the area of end-of-life and palliative care and provides clarity on which definitions are selected for this thesis. Chapter One closes with an outline of the overall thesis structure.

Reflections

I remember a previous student early on in my journey, advising that the research topic needed to be something that would hold our interest for the six years the doctorate might take. I started my doctorate journey with a different topic in mind, however, soon started to develop a professional interest in the organisational issues relating to hospice care and dementia. I took a little detour part way through, however, this topic was a contemporary issue within my professional role and one that played to my experience in organisational development, culture and service development strategy. Developing this first chapter in the thesis enabled me to constructively explore the early stages of my journey and recognise how it influenced my research.

2 Chapter Two – The theoretical lens of organisational institutionalism

Chapter One highlighted the challenge being presented to hospices by the changing demographics, and in particular the prevalence of people dying with or from dementia. As major players in the provision of palliative and end-of-life care, the hospice movement is expected to respond to this challenge and is perhaps struggling to find a viable solution at scale. In addition, Chapter One provided the rationale for taking an organisational institutionalism perspective. This chapter will more fully explore this theoretical lens and introduce core elements of the theory such as: organisational field, legitimacy and institutional work.

Organisational theory offers researchers many different perspectives coming from multiple disciplines. Literature about organisations and how they were designed and managed, started to develop during the industrial age, as executives wanted to expand their knowledge on how organisations should be designed to maximise productivity. Academic studies within the Schools of Economics and Sociology focused on the role of organisations within society, with interest growing in the cultural and social systems of organisations rather than considering them simply as production vehicles (Hatch and Cunliffe, 2013; Scott, 2008).

In such a wide and complex theoretical landscape there are multiple and often conflicting definitions. Before launching into the literature and theory of organisational institutionalism, some clarity of the definitions chosen as most relevant to some of the key concepts utilised within this thesis are detailed.

Therefore this chapter is structured in three parts:

- Part One – organisational institutionalism definitions
- Part Two – discussion of organisational institutionalist theory, institutional work and associated concepts
- Part Three – an institutional description of hospice and the application of theory

2.1 Part One - organisational institutionalism definitions

In trying to understand the concepts and arguments within organisational institutionalism or institutional theory; the theorists do not provide much comfort. Institutional theory is described as a confusing field, with differing schools of thought and conflicting interpretations (Powell and DiMaggio, 1991, Scott, 2008). The literature is described as 'a jungle of conflicting conceptions, divergent underlying assumptions, and discordant voices' (Scott, 2008, p. vii).

This section aims to provide some broad definitions of key terms prior to entering into some depth on organisational institutionalism. Further discussion on these concepts can be found in the remainder of this chapter and threaded throughout the rest of the thesis.

Organisation

This is probably the simplest concept to define. Selznick (1957) describes organisations as 'technical instruments, designed as means to definite goals' (Selznick, 1957 p.21). Formal organisations have administrative attributes such as rules, objectives, tasks, levels of authority they are designed to be a 'technical instrument for mobilising human energies and directing them towards set aims' (Selznick, 1957 p. 5). In the context of hospices, the organisation is the legally formed entity, the individually registered company and charity.

Institution

To study an organisation as an institution, Selznick writes that this means that attention would be paid to 'its history and to the way it has been influenced by the social environment' (Selznick, 1957 p.6). Social environment would include those internal and external to the organisation. An organisation becomes institutionalised over time as it develops its distinctive identity, it's sense of value, the rituals and stories and social facts culminating in an entity that is

institutionalised i.e. 'to infuse with value beyond the technical requirements of the task at hand' (Selznick, 1957 p. 22; Scott 2008).

The term 'institution' has had various definitions over time with calls from academics and researchers to reach consensus of its meaning (Powell and DiMaggio, 1991; Scott, 2008). The definition adopted in this thesis is 'an organisation with 'more-or-less taken-for-granted repetitive social behaviour that is underpinned by normative systems and cognitive understandings that give mean to a social exchange and thus enabling self-reproducing social order' (Greenwood, et al., 2008, p. 5).

It should be noted that professions are themselves institutions (Muzio, et al., 2013). Muzio et al. (2013) wrote about professional services highlighting the lack of theory and research in the area of professional institutionalisation. However, this concept could equally be applied to other professions such doctors and nurses.

Social Movement

There are several definitions of social movement, the definition that is most useful for this thesis is 'a collective acting with some continuity to promote or resist a change in the society or organisation of which it is part' (Turner and Killian, 1987, cited by Diani, 1992 p4). In the context of hospices, Dame Cicely Saunders and her network of associates were promoting a change in society relating to the care of people with terminal cancer. Social movement theory started to form in the 1960s with scholars studying collective action and demonstrating that this wasn't irrational behaviour based on protest (Davis, et al., 2005). As discussed in Section 2.3, social movement theory built on work by Selznick as he wanted to explore the tension between 'value commitments' and 'survival concern' within institutional theory (Davis, et al., 2005, p. 6). There is interest in the overlap between social movement theory and organisational theory

(Davis, et al., 2005) and this relationship is interesting in the context of organisational history and narrative e.g. a movements becoming an institution.

Identity and Culture

Identity and culture are socially constructed, therefore subjective, based on interpretation and how an individual makes sense of their environment or indeed themselves.

The concept of culture relates to an invisible, powerful, phenomenon within an organisation that can drive behaviour (Schein, 2010). Schein (2010) defines culture (in relation to a group) as 'a pattern of shared basic assumptions learned by a group as it solved its problems of external adaptation and internal integration, which has worked well enough to be considered valid, and, therefore, to be taught to new members as the correct way to perceive, think, and feel in relation to those problems' (Schein, 2010, p18). Culture becomes the norms of behaviour, action and understanding which makes things routine – i.e. the way things happen. Groups can have beliefs and values that are in conflict with others, particularly during times of change. Different groups within an organisation can have their own cultures, nested within the overall culture. For this thesis culture will relate to many components of how hospices behave both functionally and socially. Culture is part of identity.

Identity, in relation to organisations is defined by Albert and Whetten (1985) as the 'central, distinctive and enduring characteristics of an organization' (Mujib, 2017 p. 1, cited Albert & Whetten, 1985). Selznick (1957) described the 'distinctive identity' that is created via the process of institutionalisation, i.e. how the norms, values, beliefs and therefore cultures become the legitimate narrative for an organisation.

Identity in the context of this thesis relates to how hospices define themselves and each other. The thesis will consider the extent to which the distinctive identity of hospice care may be impacting the movement's ability to change. For

example, a hospice that defines itself as a provider of specialist palliative care may consider the issue of dementia differently to one that defines itself as more generalist. This example, may also relate of course, to how staff and volunteers define themselves, in particular healthcare professionals.

Meta-Organisation

'Meta-organisations are associations' (Ahrne & Brunsson, 2008, p. 3) and provide a way of describing relationships and differences between individual organisations and for example a membership body or a trade association. The relevance of a meta-organisation is explored in Chapter Two. Hospice UK is an example of a meta-organisation, hence this concept is relevant to this thesis.

Organisational field

To set up this chapter and the analytical framing for this research it is necessary to be clearer about the organisational field being researched. An organisational field relates to 'those organisations that, in the aggregate, constitute a recognised area of institutional life: key suppliers, resource and product consumers, regulatory agencies and other organisations that produce similar services or products' (Powell & DiMaggio, 1991, p. 64).

Powell and DiMaggio (1991) argue that to be considered an organisational field the following four criteria should be met:-

- i) 'an increase in the extent of the interaction among organisations in the field,
- ii) the emergence of sharply defined inter-organisational structures of domination and patterns of coalition,
- iii) an increase in the informational load with which organisations in a field must contend and

- iv) the development of mutual awareness among participants in a set of organisations that they are involved in a common enterprise' (Powell & DiMaggio, 1991 p.65).

How hospices relate to this definition is discussed in Section 2.3.

Scott (1994) builds on Powell and DiMaggio's (1991) definition promoting an organisational field as 'the existence of a community of organisations that partakes of a common meaning system and whose participants interact more frequently and fatefully with one another than with actors outside of the field (Scott 1994a: 207-208 citing himself 2012). This second definition is perhaps slightly more difficult for hospices to truly align to as whilst true, there are also frequent and fateful interactions with the NHS. This highlights the fact that an organisation can be part of multiple organisational fields.

It is reasonable to suggest that despite being individual organisations, all hospices offer broadly similar services, that they, therefore, are an organisational field as opposed to a diverse, disparate operating environment. In accepting this, it means that aspects of institutional theory, related to organisational fields may be more effective in supporting hospices than the traditional 'single' organisational theory.

Organisational institutionalism

Organisational Institutionalism is the combination of organisational and institutional thinking. It focuses on the institutional factors within the organisation (and the organisational manifestations of institutions). Organisational Institutionalism is a theory that explores 'how institutional processes shape organisations' (Greenwood, et al., 2014).

The history and formation of the hospice movement is filled with institutional processes which will be explored in this chapter and are fundamental to this thesis. Hospices' stories include charismatic founders, a drive for social action,

rituals and ceremonies and what Durkheim describes as 'symbolic systems – systems of knowledge, belief, and 'moral authority' (Scott, 2008 p. 12).

Addressing the issue of organisational factors influencing the development of services for people with dementia could be explored from an organisational perspective and focus on rational instruments such as finance, labour or capacity however, would miss the richness of hospice history and narrative which organisational institutionalism offers.

Institutional work

Institutional Work is a branch of organisational institutionalism that can bridge organisational and field level analyses, as well as recognising the duality of agency (i.e. individual action) and structure. Lawrence, Suddaby and Leca (2009) position institutional work theory as an alternative to the traditional focus of 'attention on the relationship among organisations and fields in which they operate, providing strong accounts of the processes through which institutions govern action' (Lawrence, et al., 2011, p. 1). Institutional work shifts this traditional organisational institutionalist perspective to focus on how individual action affects institutions, it is offered as a theory that is 'connecting, bridging and extending work on institutional entrepreneurship, institutional change and innovation and deinstitutionalisation' (Lawrence, et al., 2011, p. 1).

Institutional work argues that individual actions, despite being institutionally framed and shaped, have agency and can influence and create change i.e. the extent to which an individual is simply complying with the norms and expectations of an institutionalised organisation, in comparison to individuals acting directly in the creation, maintenance and disruption of institutions. What Lawrence et al. (2011) describe as either being an accomplice or an agent. In summary institutional work is a branch of organisational theory that is interested in 'the purposive action of individuals and organisations aimed at creating, maintaining and disrupting institutions' (Lawrence and Suddaby, 2006 p15).

Section 2.1 provided definitions and a brief introduction to some of the concepts that will be introduced in this thesis. The section also provided insight into how these concepts are being interpreted and defined by the researcher for this thesis. Section 2.2 now adds additional depth to the theory of organisational institutionalism.

2.2 Part Two – discussion of organisational institutionalist theory, institutional work and associated concepts

Part two of this chapter, will provide insight and discussion into the key elements of organisational institutionalism. It will provide an overview of the history of thought in this tradition, highlighting some differences between old and new institutionalism, and why these are relevant to hospices. It will describe and discuss concepts that are essential in addressing this research topic for example legitimacy, the role of agency and how this links to the theory of institutional work and that help in understanding processes of institutional change. The chapter concludes with a discussion of two models that, taken together, form the conceptual framework for the research.

Background of organisational institutionalism

All organisations can become institutionalised to a certain extent; however, hospices have specific traits as organisations that are different to those of the private or public-sector entities. They are predominately funded by the local community and are staffed more by volunteers than paid workers. This would indicate that they are valued by recipients of care and the wider community. Scott (2008) maintained that institutionalised organisations that are infused with value, are no longer 'expendable tools', that the organisation creates a 'character structure and distinctive identity' leading to a need to maintain the organisation, preserving the values (Scott, 2008, p. 22). The challenge of the development of dementia services within hospices organisations, resembles much of the discourse on organisational institutionalism. For example, the distinctive identity of the hospice movement, the reality of its history, is caring for people with

cancer. The need to raise circa 65% of funding from voluntary sources automatically ties hospices into a relationship with its local community, requiring a demonstration of its societal value, through stories and acts that inspire people to raise funds. This local value, is also required to fill thousands of volunteering roles. Therefore, it is considered that preserving the perceived social value of a hospice organisation is directly linked to its survival. As a clinical organisation, there are also issues of professional identity with registered healthcare professionals who also have views on whether caring for people with dementia, is aligned to their sense of self, which will be explored as part of the discussion in chapters six to eight.

Organisations were recognised as an important phenomenon for study from the 1950's with institutionalism becoming gradually connected to the discourse around organisational behaviour (Scott W. R., 2008). There is going to be no attempt in this thesis to provide a historical overview of organisational theory, the contributions of scholars like Weber, Durkheim and Marx has been well documented (Hatch & Cunliffe, 2013, Line in Publishing, 2014, Powell & DiMaggio, 1991). As the sociological interest in organisations and institutions grew, the contributions of theorists such as Mead, Blumer, Berger and Luckmann became important in raising the question of how organisations, as social contexts, were formed and maintained: their contribution from a philosophical and methodological perspective is briefly discussed in Chapter Four (Section 4.3). However, in what follows, some of the key developments of institutional theory and associated concepts are reviewed, as these have informed the analysis of organisations.

Scott, (2008) provided an overview of the history of institutional theory from the late 19th century to the beginning of the 21st Century, reflecting three different schools of thought; economics, political science and sociology. Powell and DiMaggio (1991) argued that the traditional economic or political lens through

which to study institutions, failed to take into account the social context suggesting that empirical studies exposed an inconsistency between these approaches and what was actually observed during the research.

Philip Selznick, an early pioneer of what is now known as old institutionalism, was interested in unintended consequences and how the outcomes of organisational actions are constrained by their environment (Scott, 2008). In 1957 he stated that 'institutionalisation is a process. It is something that happens to an organisation over time, reflecting the organisation's own distinctive history, the people who have been in it, the groups it embodies and the vested interests they have created, and the way it has adapted to its environment... In what is perhaps its most significant meaning, 'to institutionalise' is to *infuse with value* beyond the technical requirements of the task in hand' (Selznick, 1957 p16-17, italics as per original text).

It is essential therefore that the distinctive identity of hospice is reflected upon, in attempting to understand the institutional context of the hospice movement, looking for example at its history and the extent to which an identity constructed from cancer can be changed, if this is indeed desirable. The challenge is not just one of capacity, capability and resources but one of identity.

New Institutionalism originated by John Meyer in 1977 shifted the focus from a local unit of analysis to 'macro-influences' and considers 'non-local' environments such as sectors and professions (Powell and DiMaggio, 1991).

Whilst many similarities such as the relationship between the organisation and its environment, there are key differences between old and new institutionalism which are outlined by Powell and DiMaggio (1991) and depicted in Table 2.1 (page 35). This is not a linear process, i.e. it is not the case that an organisation is established as old and moves to new. These are two distinct theoretical schools of thought asking different questions or considering an alternative unit of

analysis. That said, it is possible that organisations have attributes of both based on their individual history and identity.

Table 2.1 - Old and new institutional thinking (Powell and DiMaggio, 1991, p13)

	Old	New
Conflicts of interest	Central	Peripheral
Source of inertia	Vested interests	Legitimacy imperative
Structural emphasis	Informal structure	Symbolic role of formal structure
Organisation embedded in	Local community	Field, sector or society
Nature of embeddedness	Co-optation	Constitutive
Locus of institutionalisation	Organisation	Field or society
Organisational dynamics	Change	Persistence
Basis of critique of utilitarianism	Theory of interest aggregation	Theory of action
Evidence for critique of utilitarianism	Unanticipated consequences	Unreflective activity
Key forms of cognition	Values, norms, attitudes	Classifications, routines, scripts, schema
Social psychology	Socialization theory	Attribution theory
Cognitive basis of order	Commitment	Habit, practical action
Goals	Displaced	Ambiguous
Agenda	Policy relevance	Disciplinary

Hospices have attributes of both old and new institutionalism which adds complexity in respect of organisational change as different perspectives from alternative schools of thought can be applied to the same issue. There are elements of hospices' history, belief and assumptions that would sit within old

institutional attributes such as vested interests, informal structure, local community, organisation and change. However, over time as the individual organisations have become part of a field, roles have become professionalised via the specialisation of palliative medicine, formal structures have developed, and there is a focus perhaps on persistence and legitimacy (which will be introduced in Section 2.2.1). Given that old institutional theory has grown out of social movement theory and hospices were developed purposively outside of the statutory sector by local interested people it would be understandable that some elements of old institutionalism exists. Equally the development of palliative medicine, the regulated professional roles required and the relationship with the NHS would naturally lean towards new institutionalism. This distinction is of value to the movement as it may well be that supporters and volunteers value the old institutional factors of the hospice being embedded in the community and the organisation being the locus rather than a professional field. However, some staff groups may associate themselves more with the field or sector. This distinction may impact the method and narrative of change.

Organisational institutionalism allows for the exploration of these types of issues, recognising the social constructs impacting an organisation. Selznick sees this as a process, occurring as an organisation is influenced by its social context and becomes a 'natural product of social needs and pressures – a responsive, adaptive organism' rather than bare, lean with a 'no-nonsense system of consciously coordinated activities' 'a rational instrument' (Selznick, 1957, p. 5).

The fundamental insight of institutional theory is that certain (symbolic) elements of institutional context influence how organisations - whether singly, or collectively - behave. Institutional context is specified variously, as 'widespread social understandings or rationalised myths' (Greenwood, et al., 2008, p. 3) and 'the rules, norms and ideologies of the wider society' (Zucker 1983: 105 cited by Greenwood, et al., 2008 p3). Meta-organisation theory is very aligned to this

thinking (see Section 2.1 and Section 2.3), the hospice movement may appear to be collectively embracing care beyond cancer through the actions of Hospice UK, however, individually hospices may not all agree and may assert its own beliefs through its use of media stories reinforcing existing social understandings.

In their seminal paper, Meyer and Rowan (1977) introduced the term 'institutionalised organisations'. Yet in describing the impact of 'institutional contexts', it failed to provide a comprehensive definition, so creating further debate and confusion. Context could, for example, refer to the very specific regulatory framework in which an organisation operates or to the most general, or abstract set of 'symbolic/cultural' influencers (Greenwood, et al., 2008). Of course, both may be true, the regulatory framework may influence symbolic and cultural factors. The regulatory framework may be used by individuals as an excuse for maintaining certain practices, for example hospices commissioned by the NHS to provide specialist palliative care services, this is a contractual framework. The referral process asks what the 'specialist need is', again a system reinforcing the patient population that the organisation has determined can access a particular service. However, in theory, symbolic or cultural influencers could create subjectivity in the system, maybe the person reviewing the referral process believes that people with dementia do not have specialist need, regardless of what is on the form. Maybe the person reviewing the referrals has personal affinity with the plight of people dying with dementia and therefore accepts the referral despite it not being the norm. Therefore, on this point by Greenwood, et al. (2008) the institutional context must look at both factors i.e. regulatory and symbolic in analysing organisational institutionalist processes or behaviours.

Within the breadth of organisational institutionalism there are some key concepts which have particular relevance in this research. The concept of legitimacy which will be introduced in section 2.2.2, became a new, dominant concept

applied in the analysis and discourse around this research topic, including in practice. The concept of legitimacy may be central to explaining why hospices have not yet responded to the challenge of dementia, i.e. is it a legitimate use of their services and skills.

2.2.1 Legitimacy

Legitimacy is defined as 'a generalised perception or assumption that the actions of an entity are desirable, proper, or appropriate within some socially constructed system of norms, values, beliefs and definitions' (Suchman, 1995 p.574).

It has already been articulated that organisations within a field, behave in a similar way to each other, i.e. offering similar services and interact with each other as part of a shared environment. Their similarity to each other stabilises the organisational field. However, if organisations within the field start to behave in less similar ways, moving away from their previous norms, then there can be a challenge to legitimacy. There may be a negative response to this challenge in whatever form it takes shape, e.g. starting a narrative as to why it is no longer legitimate to predominately care for people with cancer. This negativity could risk reputational damage with legitimating organisations, if they have a different view on what is legitimate and could therefore impact on resources (George, et al., 2006) i.e. statutory or voluntary funding. However, a challenge to legitimacy may also result in new and revised legitimate forms emerging as the field shifts towards becoming similar again, due to the tendency for organisations with a field to desire legitimacy and therefore remain broadly similar (Powell & DiMaggio, 1991).

Institutional theorists report that organisations, in fitting in their institutional and environmental context, become institutionalised by conforming to rules, myths and norms and enhancing their perception of legitimacy. Legitimacy is considered a positive thing as it can improve chances of survival and attracting resources. However, whilst legitimacy can enable an organisation to be part of

an accepted field, i.e. an organisation operating as a hospice in a similar way to the other hospices within the movement, it can also create constraints. Zietsma and McKnight (2009) describe this constraining element as an 'iron cage' creating an image of an organisation trapped by its field and the need for legitimacy. The constraints may be that the organisation doesn't feel able to pursue service developments that are very different to the norms within the field at the risk of this being seen as not legitimate by others in the field and losing legitimacy. Equally the constraints may be that by remaining legitimate, what would otherwise be sound business decisions are avoided. The adoption of practices from other organisations within a field, may create legitimacy, but it may also be at the cost of efficiency or quality (Greenwood et al., 2008, Meyer and Rowan, 1977; Lawrence, et al., 2009). For example if a large element of the hospice movement proved that care for people with dementia was legitimate and a number of large hospices decided to change, then the question might be the extent to whether the cost of change for some hospices within the field is a sensible business decision and whether all hospices can adapt services, remain financially viable and maintain the high quality of care that is part of their identity.

Zietsma and McKnight argue that if the iron cage is breached the impact would be deinstitutionalisation and a need for a new institution to arise with a new legitimacy to stabilise the field (Zietsma & McKnight, 2009). For example, if there was a convincing argument for a new normal, e.g. hypothetically, cancer is a long term condition and resources should be shifted to fund care for people dying from other illnesses such dementia, then a revised narrative would be established. This new narrative would create tension and possible change within the movement. The field might then start to fragment i.e. it would start to 'deinstitutionalise' as the old narrative was questioned. A new institution, maybe, for example, a partnership of those hospices that have started their new narrative would need to take shape with a convincing new story of legitimacy that stabilises the field or hospice. Or meta-organisation recognition and approval of a new

type of hospice that extends care to patients with dementia creating legitimacy and an impetus for change. The process of deinstitutionalisation and reinstitutionalisation is discussed further on Figure 2.1, with reference to Greenwood et al.'s model (2002).

George et al. (2006) agree that legitimacy has an impact on decision making with organisations favouring decisions that are 'legitimacy related'. The suggestion is that most of the legitimacy related challenges relate to control or resources (George et al., 2006; Oliver, 1991) and that the 'gain or loss of legitimacy is linked either to the loss or gain of resources, or to the loss or gain of control' (George, et al., 2006, p. 352). Making decisions that are not aligned to the legitimated norms can result in criticism from powerful actors or result in a loss of resources. Governmental or regulatory bodies and public opinion can provide legitimacy, i.e. endorse an institution (Deephouse, 1996). Hospices are given legitimacy by regulatory and statutory bodies such as the CQC and the NHS. Similarly, members of professional groups employed within the hospice such as doctors, nurses, allied healthcare professionals can also be given legitimacy by their professional bodies. For hospices, due to their role in society, legitimacy is also given via local communities who buy into the social values of hospice care and contribute significant financial and manpower resources.

Legitimising organisations can provide legitimacy by mechanisms such as membership or compliance, Trank and Washington (2009) write that these organisations are often 'the public vehicle and symbolic touchstone' and that they are often the 'focal and public face of complex institutional arrangements' (Trank & Washington, 2009, p. 236). In the context of hospices, in addition to the social actors mentioned above, Hospice UK could also be seen as a legitimating organisation, however, it is not entirely consistent with Trank and Washington's (2009) view as within local communities it is the hospice itself that is the 'public vehicle and symbolic touchstone'. Hospice UK's role can confer legitimacy not

only via membership but also through the provision of resources in the form of grants for specific pieces of work i.e. recent grants to support services for people with non-malignant disease and previous grants for dementia suggesting it is legitimate for hospices to develop services in these areas of patient care.

The extent to which the 'concept' of legitimacy is impacting the development of hospice services for people with dementia will be explored in Chapters Six - Eight. Legitimacy can work at all levels; field, organisational and individual.

A recurrent theme in organisational institutionalism literature is the issue of 'agency' i.e. the extent to which an individual has free will. This concept, discussed in Section 2.2.2 is important ahead of introducing institutional work theory.

2.2.2 Agency

The issue of individual agency and institutional change is described by Seo and Creed as a 'paradox'. This relates to what extent individuals simply replicate and comply with institutional processes, norms and behaviours i.e. structure, or the extent to which individuals influence, challenge and change the institutions in which they work i.e. agency (Seo and Creed, 2002; Battilana and D'Aunno, 2009; Lawrence, et al., 2009; Garud, et al., 2007). Holm (1995) asks the question 'how can actors change institutions if their actions, intentions and rationality are all conditioned by the very institution they want to change?' (Holm, 1995, p.398). Seo and Creed ask 'when and how do actors actually decide to revise behavioural scripts when their actions and thoughts are constantly constrained by the existing institutional system?' (Seo and Creed, 2002, p.224).

In a similar way to organisations desiring legitimacy within their environmental context, early institutional theory also propose that this equally applies to human agency, i.e. employees conforming to the norms and accepted processes of an organisation. However, this view does not explain how institutions change, hence the 'paradox'. The relationship between structure and agency is a common

theme in institutional theory (Battilana and D'ahunno, 2009; George et al., 2006, Greenwood et al., 2002, 2008, Seo and Creed, 2002) and in sociological theory, more widely. Giddens' (1984) aims to connect the roles of social actors within structures and presents this as a duality in that 'the constitution of agents and structures are not two independently given sets of phenomena' (Giddens A, 1984, p25). Giddens' suggests that 'social actors draw upon and reproduce structural features of wider social systems' (Giddens A, 1984, p24).

There is criticism of research (notably leveled at new institutional research) that focuses too much on structure and underplays the role of individual agency. However, there is equally a counter argument that research focusing on agency often considers the role of 'powerful actors' (Coule & Patmore, 2013, p. 654) or other 'heroic models of actors' (Garud, et al., 2007, p. 961) and 'modern princes' (Garud, et al., 2007, p. 963) rather than a wider view of who may use their agency. Some people may be more constrained by the institutional environment than others (Battilana & D'ahunno, 2009).

Giddens' (1984) duality of structure and agency, allows that human agency, despite organisational institutionalism, does not simply conform to institutional norms but also has the capacity to use their knowledge, experience and resources to act in ways other than those 'taken-for-granted social rules and technological artefacts' (Garud, et al., 2007, p. 961).

The term 'institutional entrepreneurs' was proposed as a way of countering the excessive emphasis on structure in new institutionalism. Garud, et al (2007) credits the concept of institutional entrepreneurs with the reintroduction of 'agency, interests and power into the institutional analysis of organisations' (Garud, Hardy, & Maguire, 2007, p. 957). Institutional Entrepreneurs are key influencers who can utilise power and resources to form or change institutions in which they have an interest (Garud, et al., 2007). Institutional Entrepreneurs see past the constraints of institutions and influence a shift in ways considered legitimate to

reinstitutionalise an alternative model. The nature of change in this context must be something significant enough to warrant the disruption of the field, hence why in Greenwood et al.'s (2002) model (Figure 2.1), the change is initiated by a sociological, technological or regulatory jolt (Greenwood et al., 2002 p 60).

2.2.3 Institutional work theory

Institutional change, however, is not only the realm of institutional entrepreneurs but can be the day to day actions of people. There are other actors within institutions, those who might be considered to have less power or access to resources who may also influence their maintenance or disruption. (Coule & Patmore, 2013).

Institutional work, a branch of organisational institutionalism can bridge organisational and field level analyses as well as the duality of agency and structure. The impact of the individual on the institution was lost from much of the neo-institutional organisational studies (Lawrence, et al., 2011). Although Berger and Luckmann (1967) as early thinkers on the concept of institution recognised the role of individuals and proposed that repeated interactions create habituated actions that are the early stages of institutionalised thinking (Berger & Luckmann, 1966). Lawrence, Suddaby and Leca (2009) position institutional work theory as an alternative to the traditional focus of 'attention on the relationship among organisations and fields in which they operate, providing strong accounts of the processes through which institutions govern action' (Lawrence, et al., 2011, p. 1). Institutional work shifts this traditional organisational institutionalist perspective to focus on how individual action affects institutions. It is offered as a theory that is 'connecting, bridging and extending work on institutional entrepreneurship, institutional change and innovation and deinstitutionalisation' (Lawrence, et al., 2011, p. 1). Institutional work theory argues that individuals, despite being institutionalised, have agency and can influence and create change.

In summary institutional work is a branch of organisational theory that is interested in 'the purposive action of individuals and organisations aimed at creating, maintaining and disrupting institutions' (Lawrence and Suddaby, 2006 p15). The theory can be applied at individual level or via the acts of groups of actors (e.g. formal groups and organisations), however, for the purposes of this thesis, focuses on acts of institutional work by individuals. Institutional work theory argues that actors, despite being institutionalised, have agency and can influence and create change. The extent to which an individual is simply complying with the norms and expectations of an institutionalised organisation in comparison to individuals acting directly in the creation, maintenance and disruption of institutions, is variable, producing what Lawrence et al (2011) describe as either accomplice or agent.

Muzio, et al., (2013) in their research on professions and institutional change recognise a connection between institutional work and identity work within professions. Recognising that people are both working in an institutionalised context and have the ability to express agency also connects to identity theory i.e. how someone makes sense of themselves, how their interactions with others can shape their social understanding of both their identity and their place in society and in this case their role. Goffman (1961) suggests that 'the study of every unit of social organisation must eventually lead to an analysis of the interaction of its elements' (Goffman, 1961, p. 7). Its elements in this case being individual agency, how they make sense of themselves, the hospice they work in, the changing environment, the community, the profession etc. Goffman (1961) articulates this in his essay on role distance. He proposes that self-image will be influenced by the job description and person specification and how individuals become attached to their position and role. This of course is critical, if how we make meaning of ourselves and others in the workplace is to a certain extent based on self-image and role identity. This can in turn influence how we interact with each other i.e. based on symbols such as uniform, job title or organisational

or professional hierarchy. Then one would imagine that acts of institutional work, our use of agency is influenced by our sense of self, i.e. self-image.

In the context of hospice, exacerbated by the specialisation of palliative care in 1987 issues related to role, professional identity and self-image may be associated with the ongoing dominant association with cancer. This association may drive acts of institutional work.

2.2.4 Maintaining and disrupting institutions

The key perspective of institutional work theory is the actions relating to creating, maintaining and disrupting institutions. The thesis is interested in acts that are maintaining or disrupting the status quo of the dominance of hospice care for people with cancer in comparison to dementia.

Maintaining

The issue of maintaining institutions is central in addressing the research question, However, there has been less research in this area (Lawrence and Suddaby, 2006; Coule and Patmore, 2013; Scott 2001; Scott 2008). The very nature of an institution involves reproducing processes, behaviours and beliefs; however, this doesn't mean that no action takes place. Maintaining actions involve 'supporting, repairing or recreating the social mechanisms that ensure compliance' (Lawrence & Suddaby, 2006, p. 230). In empirical research six forms of institutional work relating to maintaining were identified, which can be grouped into two categories.

- i. 'enabling work, policing and deterring' are actions that focus on rules-based compliance and
- ii. 'valourizing/demonizing, mythologizing and embedding/routinizing are actions related to maintaining 'existing norms and belief systems' (Lawrence and Suddaby, 2006 p.230).

Valourizing and demonizing are acts that maintain institutions by 'presenting positive and negative examples that show the normative foundations of

institutions' (Fredriksson, 2014, p. 323). This element of maintenance includes where 'actors identify and evaluate the moral status of participants in the field' (Lawrence and Suddaby, 2006 p. 232) e.g. perhaps where specialist palliative care healthcare professionals maintain the status quo by commenting on the moral value of their profession caring for people with dementia e.g. does it require specialist care. Mythologizing actions focus on telling the positive stories of an institution's history to reinforce the perceived value e.g. continuing to tell stories of the impact of caring for people with cancer. Valourizing, demonizing and mythologizing institutional work relate to stories, narrative and discourse whereas embedding and routinizing is about how day to day practices reinforce norms. An example of embedding and routinizing would be using patient referral criteria or including dementia experience on a person specification.

There is some debate as to whether stability is a normal organisational form due to institutionalised behaviours, systems, contractual obligations and regulations (Scott, 2008) or whether maintenance is more problematic and requires actors to ensure compliance to norms, processes and beliefs (Giddens, 1984), it only exists 'to the extent that actors are able to continuously produce and reproduce it (Scott 2008, p.128). It is also proposed that maintenance is due to a lack of appetite to change and inertia, that change is 'difficult and dangerous' (Scott, 2008, p. 128). Hospices have broadly maintained their organisational field for fifty years with change only being around the margins. Lawrence and Suddaby (2006) note that acts of institutional maintenance are often due to changes in the environment and how actors respond to them. This is important and reflects earlier discussion on the issue of legitimacy, if actors do not believe an action is legitimate they may exercise acts of institutional work designed to maintain current practice e.g. perhaps demonizing the proposed change or valourizing existing work or further reinforcing current systems.

Legitimizing organisations also have a role in institutional work. Hospice UK, the Care Quality Commission and the NHS can act in ways that maintain or disrupt the accepted norms of hospices at organisational and field level (Trank & Washington, 2009). Maintenance may involve actions designed to retain an organisation's strategic position, resources or power within the institutional field (Lawrence & Suddaby, 2006).

Zilber, (2009) conducted a multi-level narrative study on symbolic institutional maintenance at a rape crisis centre highlighting how stories are translated, understood and socialised by members of the institution. Her study demonstrated through the use of narrative, the interactions between actions that are about compliance and process and also those that are about beliefs (Zilber, 2009). Zilber highlighted acts of institutional work relating to embedding and routinizing such as the recruitment practices, mandatory training and the process of logging calls. Zilber also explored the narratives used within the centre and how they related to institutional maintenance and how members understood the organisational story. She concluded that "institutional change does not involve the creation of new meta-narratives, nor the reproduction or existing ones, but demands the *radical transformation* of an established meta-narrative" (Zilber, 2009, p. 230). Whilst the focus of attention of the study was community and organisation rather than organisation and field as per this thesis, the similarity between the two studies is the importance of recognising how the symbolic nature of the institution at field level and organisational level is understood. (Zilber, 2009, Lawrence, et al., 2009).

Disrupting

Disrupting an institution is defined as 'attacking or undermining the mechanisms that lead members to comply' (Lawrence & Suddaby, p.2006, p. 235). Disruption may be pursued 'where existing institutions do not meet the interests of actors who are able to mobilise sufficient support to attack or undermine these interests'

(Lawrence and Suddaby, 2009 p287) and 'may be seen as a precursor or stage in the process of institutional change' (Greenwood et al, 2002 cited by Lawrence and Suddaby, 2009 p287).

Three forms of institutional work related to disrupting institutions are identified in empirical research, however, Lawrence and Suddaby find little evidence of points ii and iii below, with most examples being included in point i:

- i. 'disconnecting sanctions,
- ii. disassociating moral foundations and
- iii. undermining assumptions and beliefs' (Lawrence & Suddaby, 2006, p. 235).

Disconnecting sanctions which also include rewards might be NHS clinical commissioning groups using grants and contracts to 'force change'.

Disassociating moral foundations might include the questioning of norms and values around cancer dominance versus equity, maybe reminding people that Dame Cicely Saunders always had some long stay patients (Boulay, 2007) and that she would have embraced the deficits in care for people dying with dementia, therefore undermining some of the normative beliefs prevalent within contemporary hospice discourse.

Undermining assumptions and beliefs may well have relevance in the case of dementia. There is potential for preconceptions around the care of people with dementia preventing change and encouraging acts of maintenance. Challenging or influencing these assumptions and beliefs may be key if hospices are going to respond to the need for services for people dying with dementia.

Individuals engaged in disruption can act in ways that may be seen to support non-legitimate practice or challenge belief systems shared by the majority of actors within an institution. Whilst there has been research around

deinstitutionalisation as a process (Oliver, 1992) and around institutional change, there has been very little focusing on disruptive acts of institutional work.

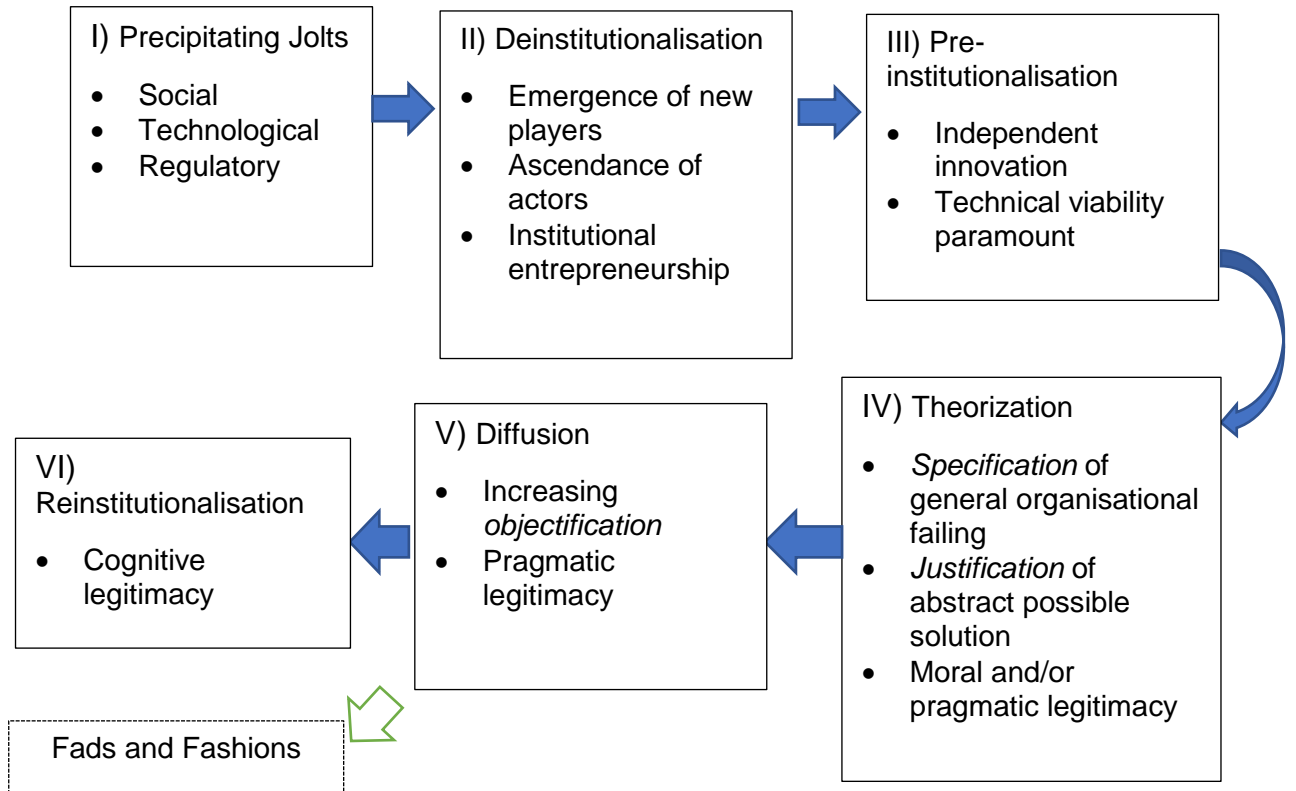
Institutional work should not be seen as linear i.e. maintain or disrupt. For examples Muzio et al. (2013) cite Suddaby and Viale (2011, p 427) as reporting that professionals have adapted and created a 'schizophrenic ability to conform to the pressures of their employing organisation, while, simultaneously, using the resources and power of the organisation to initiate profound social change and the level of the organisational field (Muzio, et al., 2013, p. 710). This ability to both comply and disrupt is evident within hospices and is demonstrated in Chapters Six - Eight.

2.2.5 Institutional change

Institutionalisation suggests that individuals in their organisations (actors) tend to conform with what is expected in terms of behaviours and actions and are perceived to be limited in having any degree of agency (Battilana and D'Aunno, 2009, Seo and Creed, 2002, p. 223). Therefore there is a question as to how change happens in a highly institutionalised environment. Greenwood et al. (2002) believe that institutional theory and change are not incompatible and use the term 'isomorphic convergence, which implies movement from one position to another' (Greenwood, et al., 2002, p. 59.). Despite appearing to be static, institutionalised organisations and fields are constantly evolving (Greenwood et al., 2002).

Battilana and D'Aunno (2009) state that institutional theorists started addressing the issue of change from the late 1980s. There are a number of diagrams describing institutional change. Figure 2.1 describes a model of change that Greenwood et al., (Greenwood, et al., 2002) created from relevant literature within the field of institutional theory.

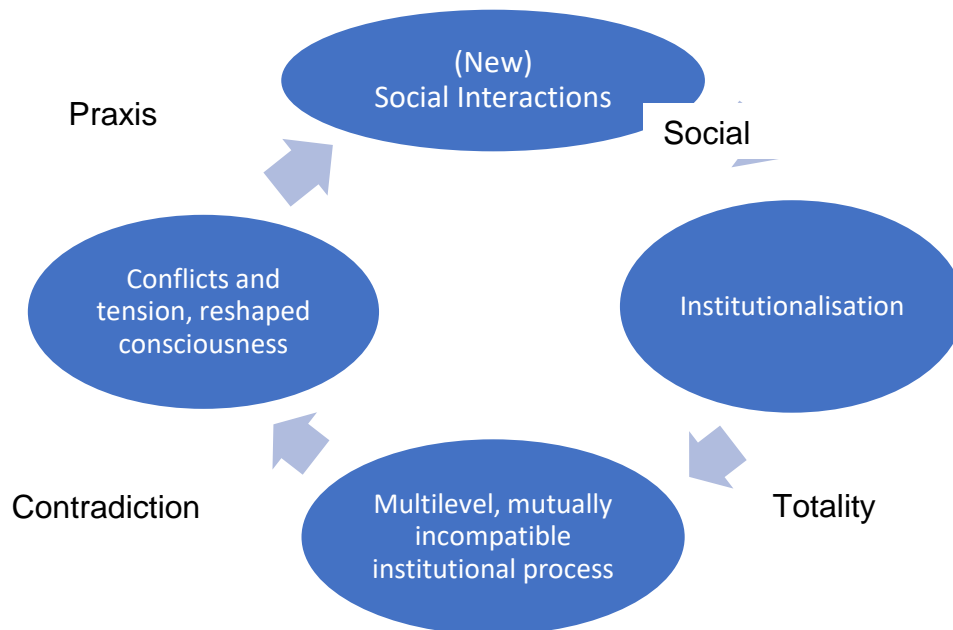
Figure 2.1 – Stage of institutional change (Greenwood et al., 2002 p. 60)



Greenwood et al's model (2002) shows a complete lifecycle of change and focuses on stages of institutional change and how following a 'jolt' in this case the prevalence of dementia, the process of desinstitutionalisation commences which takes place when the norms, beliefs of the institution are no longer believed to have social value (Clemente & Roulet, 2015). Through these stages there can then be a process of reframing the norms of an institution until they may become adopted and reinstitutionalised as new norms. This model might be used to map an organisation's or a field's position against these stages.

An alternative approach to institutional change is offered by Seo and Creed (2002) in Figure 2.2.

Figure 2.2 Institutionalisation and Institutional Change: Processes from a Dialectical Perspective (Seo and Creed, 2002 p. 225)



Seo and Creed's (2002) model is taken from a Dialectical Perspective to demonstrate institutional processes. A dialectical perspective is a way of viewing social life based on Marxists views (Seo and Creed, 2002). This model shows how ongoing interactions can challenge the status quo of insitutionalisation and lead to conflicts that reshape and lead to new perpectives that are then in turn insitutionalised.

Seo and Creed's (2002) view is built on a theory of 'praxis' a type of human agency 'political action embedded in a historical system', their model 'alerts us to the ways in which insitutional formation and change are the outcomes of political struggle amond multiple social constituencies with unequal power' (Seo & Creed, 2002, p223). It could be argued that people with dementia are a social consituency with unequal power and that those individuals within hospices driving the development of services for people with dementia are looking to emancipate this group to argue for equal access.

In the context of this thesis, Greenwood et al.'s (2002) model has greater possibility for application within the field of hospice than Seo and Creed's. Greenwood et al.'s (2002) model provides examples of 'jolt's which are external and influencing the direction of an institution rather than perhaps Seo and Creed's (2002) view of internal political activists waiting for an opportunity to mobilise. That said, the stage of deinstitutionalisation in Greenwood et al.'s (2002) model does accommodate the sort of internal change agents that 'Seo and Creed's (2002) model has embedded in its thinking.

Both models have merit, however, this thesis is focusing on dementia as an external sociological 'jolt' rather than perhaps one of inequity and injustice and therefore analysing the question from the perspective of Greenwood et al.'s (2002) model makes most sense. However, the data may present views that, from the individual participant's perspective, are more consistent with Seo and Creed (2002). The combination of institutional work and organisational institutionalism and the concept of legitimacy for example will pick up any themes around inequality and therefore those views are accommodated in this research design.

2.2.6 Decoupling

Decoupling is a concept in institutional theory that maintains the institution to avoid deinstitutionalisation; it describes how actors can navigate issues of legitimacy and change. A decoupling strategy can enable an institution to both maintain its norms, beliefs and narrative whilst also being involved in possibly nonisomorphic activity (George, et al., 2006, Hirsch & Bermiss, 2009). This approach may avoid deinstitutionalisation in that the existing social value is maintained and boundary work can grow outside of the institution with different structures of organisation. It sounds like a model that can achieve the best of both worlds for actors pursuing areas of interest, such as dementia in the context of hospices. It is for this reason that decoupling is introduced (George, et al.,

2006, Hirsch and Bermiss, 2009). However, it could also be argued that decoupling is avoiding the problem of an institutionalised organisation that requires more transformational change, therefore in adapting 'decoupling' it is essential to be sure that the 'institutionalised' organisation is functioning efficiently, and meeting its business purpose in a sustainable way. An example of the application of decoupling is presented in Figure 6.2.

Part two of Chapter Two has provided depth and discussion on some of the relevant concepts within organisational institutionalism and associated theories. The theory provides both theoretical insight and the use of a new language through which to explore the field of hospice care. The final part of Chapter Two will start to apply organisational institutionalist theory and demonstrate how this theory can be applied to the narrative of hospice care. The detail of how this theory will be applied is then described in Chapter Four.

2.3 An organisational institutionalist perspective on the formation of the hospice movement

The history of the hospice movement is told in Chapter Three and therefore does not need to be repeated here, however, this section will start to apply the theory and language of organisational institutionalism to the narrative of hospice. Dame Cicely Saunders spent ten years developing her concept of a hospice and during this time through her speaking events, her writing and her networking she created a call for social change in the care for people with terminal cancer including the way the relatively new NHS was caring for this group of people (Boulay, 2007, Clark, 2016 i). The development of a social movement was alongside her planning for an organisation i.e. a legal entity. The hospice movement may not be a social movement to the same scale as civil rights or many of the other campaigning causes, nevertheless she created an impetus for change that resulted in a network of hospices across the country with the majority being established outside of the NHS. It is worth therefore describing the

connection between social movements and organisations as this is part of hospices distinctive identity and history.

Hospices are described as a 'movement' and arose from the need for social action in relation to care for people dying with cancer. Social Movement Theory and Organisational Theory developed independently from each other, with some cross pollination (Davis, et al., 2005, Stekelenburg, et al., 2013). Social movements are a form of collective action. Giddens & Sutton (2013) describe how achieving goals or social change is not always possible within the political, governmental system and how alternative methods arise. Social Movements are one of the ways that people or groups can achieve social change outside of these institutional structures. Dame Cicely Saunders purposively chose to establish St Christopher's outside of the existing healthcare institutions to enable the freedom and innovation she felt was needed (Boulay, 2007).

Blumer (1969), one of the leading theorists on social movements, developed a model of four stages of their development cited by Giddens and Sutton, (2013):

- i) 'social ferment' i.e. where there is concern about an issue but there is no organised approach;
- ii) 'popular excitement' where the concern or issue is better articulated;
- iii) 'formal organisations' where a structure is created and finally
- iv) 'institutionalisation' where the movement is accepted as part of society.

If this is the case, then there should be no surprise that the hospice movement at fifty years old is now institutionalised. Regardless of the fact that social movements that become organisations can become institutionalised that does not change their historical narrative. In the context of hospices, the fact that the term movement is still used means that it has remained as part of its current identity not purely its historical one.

Social movement theory has researched issues of why and how new movements are created and under what circumstances they evolve and succeed (Davis, et al., 2005). There are similarities between how social movements use framing, i.e. symbols and metaphors to tell their story and therefore garner support for their cause and how institutionalised organisations use cognitive forms of expression to create legitimacy and express social value (Powell and Dimaggio, 1991; Campbell, 2005). Hospices tell patient stories as a way of garnering resources (financial and volunteering). Patient's families often send cards and provide thanks for the difference the hospice has made to their loved one. The symbols, metaphors, cognitive forms of expression and social value are all key elements of the modern hospice. These can be seen in hospice buildings, in press releases and on websites.

Following the foundation of St Christopher's Hospice, other people from medicine, religion and within communities were inspired to establish hospices in their locality. There were a few hospices established by the NHS, however, most were set up as independent charitable organisations. Help the Hospices (now Hospice UK and will be referred to as such throughout) was established in 1984 to support the growing number of individual charities via grant funding and lobbying. Hospice UK has restrictions on what type of organisation is eligible to be a member, which when it formed left out some of the large national charities such as Macmillan. There was a debate nationally about the need for a single entity to represent all organisations involved in palliative care and therefore the National Council for Hospice and Specialist Palliative Care Services (later named as National Council for Palliative Care was founded in 1991 (Clark, 2016 i), this entity merged with Hospice UK in 2017.

Hospice UK is what Ahrne and Brunsson (2008) describe as a meta-organisation. A meta-organisation is designed to act in the best interests of all its members; membership is optional. A meta-organisation has a horizontal rather than vertical

hierarchy, i.e. Hospice UK is not a parent company of the individual members and all hospices are equal. Ahrne and Brunsson argue that meta-organisations act differently to other organisations as their members are not employees but organisations who have their own autonomy and identity. The ways of working for a meta-organisation must be negotiated with their members, there is no right of authority. One of the perceived benefits is that it brings an order to what would otherwise be a fragmented part of the external environment and contributes to the functioning of an organisational field (Ahrne and Brunsson, 2008). In the context of hospices, the meta-organisation can help create a national identity that lobbies the statutory sector for funding changes to policy, it can facilitate interactions between members including sharing of data to create an amalgamated view of the hospice movement and establishing special interest groups such as the Dementia Community of Practice. There is potential for tensions within meta-organisations. Membership is at its strongest when members are all similar with similar goals for their organisations, however, there can be difficulties if some organisations want to pursue different goals as this can destabilise the identity and functioning of the entire structure (Ahrne and Brunsson, 2008). As was discussed further on this chapter under the heading of 'legitimacy', meta-organisations can play a key role in influencing the direction of its members, however, cannot on its own achieve change. The concept of a meta-organisation is important in this thesis given the potential influence of Hospice UK on the field.

The emergence of a membership body, Hospice UK, started to create the conduit for the organisational field of hospice care. Powell and DiMaggio (1991) state that an organisational field must be defined on the basis of empirical investigation and that they must meet four criteria of institutional definition or structuration (see Section 2.1)

To demonstrate the applicability of this element of organisational theory to this thesis it is necessary to stipulate that hospice care is indeed an organisational field. There are numerous groups established regionally and nationally where hospices are interacting e.g. the Executive Clinical Leads forum, Senior HR Leads forum, Chief Executive joint meetings, education networks etc. There are both regional and national inter-organisational structures and patterns of coalition. The informational load increased to help Hospice UK form a national picture of the hospice movement. The level of interaction between hospices, locally, regionally and nationally means that there is no doubt that the fourth category of structuration is evident within the field of hospice care.

A hospice will belong to a number of organisational fields. For example, if the organisational field was concerned with the delivery of palliative care in Staffordshire, many of the stakeholders would be similar in the network map (Figure 1.1), however, the definition of who is in or out of the field would be drawn differently. The organisational field that this thesis is interested in is that of the English hospice movement.

Despite the hospice movement being an organisational field with a strong collective identity and voice, each hospice is accountable only to its governing board and its charitable objects. For each hospice, the decision to establish support for people with dementia, is a strategic one that carries potential risks. The risks are not only factors such as financial sustainability but also the potential impact of challenging the identity of the organisation. Adding provision for dementia care to the activities of the hospice would alter the combination of defining characteristics of the institution. As Chapter One suggests, these are substantially bound to care for people with cancer. There is, also a collective dimension. If all hospices were to agree, collectively, to respond to the need for dementia care, this could change the relationship between hospices and other healthcare partners such as the NHS and social care services. It could also

change the relationship between hospices and their local community putting charitable funding at risk or if the change of focus was widely welcomed, maybe bring in more voluntary funding.

This section has aimed to provide an amalgamation of some of the theoretical concepts and language alongside organisational elements of the hospice story. The next chapter will focus on the literature relating to the historical background of care for people with dementia and people with cancer and the development of the hospice movement. It will also discuss the applicability of hospice care for people with dementia and introduce other research studies that are relevant in considering hospices from an institutional perspective.

Chapter Summary

This chapter has proposed that hospices are institutions operating in an organisational field and in doing so has introduced the reader to several key concepts relevant to organisational institutionalism and institutional work theory and how they relate to hospice organisations. This section recognises the complexity and breadth of literature on organisational theory and does not aim to provide a comprehensive account but to provide a focused understanding.

Tracing hospices history reflecting on influences from social movement theory and the evolution to institutionalisation provides insight into the complexity of having a foot in two theoretical schools i.e. old and new institutionalism which can be contradictory and confusing with regards to creating a new shared narrative of hospice care for people with dementia, if that is indeed desirable.

A model of change is presented as having perhaps some resonance with the hospice movement that might provide the ability to consider whether these stages of change have been followed or if not whether that creates any perspectives that add to the debate.

The chapter has attempted to provide broad understanding of key concepts and some detail and discussion on critical concepts such as legitimacy that are

relevant in addressing the research questions and clarifies where the research is situated i.e. the organisational field of hospice care. It discusses some of the benefits and constraints of belonging to an organisational field and considers the roles of Hospice UK as both a legitimating organisation and a meta-organisation that gives a clear presence to the hospices, collectively, within the wider field.

Institutional work is proposed as a relevant theory to analyse elements of the qualitative data collected in the field work. Institutional Work Theory is a branch of organisational theory that highlights how the actions of individuals and organisations/collective actors can contribute purposefully to creating, maintaining and disrupting institutions. An analysis of the types of institutional work that are evident in current practice, and the extent to which these may be contributing to, or constraining change in the hospices community forms the core of Chapters six and seven.

Reflection

This chapter was challenging since there is just so much literature relating to organisational theory it is such a vast subject. I had intended to focus on issues of culture and was familiar with writers such as Edgar Schein and his three tiers of cultural analysis (Schein, 2010) and Johnson's cultural web (Johnson, 1990). In fact in module four of the taught section of the doctorate, I tested both Schein's and Scholes' models to see which would be most relevant. However, further reading and supervision discussions introduced me to institutional work theory and from there organisational institutionalism. These theories made absolute sense to me (eventually), and supported a far more in depth view of cultural factors and organisational change. Gaining confidence in discussing and describing the theories I was applying was a key turning point leading to the publication of my first academic article and presentations on a theoretical model I was able to develop (see Chapter Seven).

3 Chapter Three - review of the literature

This chapter will review literature that is relevant to understanding the historical and policy context within which this study is situated. As discussed in Chapter Two, the history of the formation of the hospice movement is an integral part of the organisational narrative at individual hospice and at field level. Some key moments in the movement's history underpin how stakeholders interpret and understand the field and their place in it. Cognitive understanding of the position of hospices in relation to dementia care, potentially reshapes the field of palliative and end of life care.

It is also important to highlight the relevance of hospice care for people with dementia. If dementia is not relevant, then the research would not be asking legitimate questions of the hospice movement. Policy literature identifies the positions within the external environment and the views and actions of 'legitimising organisations' such as the NHS, Hospice UK and national dementia charities. Finally, the chapter will discuss empirical studies to see where other studies provide insight on the factors influencing hospices development of services for people with dementia.

Before launching into the literature, the chapter will describe the search criteria strategy used, the categories of literature that are discussed and general structure for this part of the thesis.

3.1 Literature review search criteria

The literature search strategy started with a clear, structured review of the research topic and questions. To help formulate the questions formal search strategies including the use of PICO and ECLIPSE were considered. Within health research PICO is often utilised (Wildridge & Bell, 2002), standing for Patient, Intervention, Comparison and clinical Outcomes. However, PICO is deemed unsuitable for health management or health policy studies as often

comparison studies and clinical outcomes do not apply (Wildridge & Bell, 2002).

Therefore, ECLIPSE was developed (see Table 3.1, page 62):

- E standing for Expectation (what is the information needed for),
- Client group,
- Location,
- Impact (what is the change in the service),
- Professionals and Service (for which service is the information needed)

(Wildridge & Bell, 2002).

ECLIPSE was selected as the most appropriate search strategy for this research and utilised for two critical elements of the literature search that required a structured search of many health databases (see Tables 3.2, 3.4, Page 66,70). A planning framework was utilised from a NHS guide to structure the search strategy (South Central Healthcare Librarians, 2013). The framework seeks to build search criteria based on the ECLIPSE acronym and ensures the researcher is considering alternative words. In using the framework, the researcher is determining inclusion and exclusion criteria, for example in this research focusing in on England and the impact on hospice services and excluding both the rest of the UK and international examples in addition to palliative care services outside of hospice.

The table below shows how ECLIPSE was applied to this research topic.

Table 3.1 demonstrates how alternative words extend the literature search, particularly where there is limited data. For example adding terms such as institution, culture and change when gaps in data re hospices and organisation emerged. This created an element of ECLIPSE being an iterative tool being reflected upon during the searches.

Table 3.1 - Research topic – hospice services for people with dementia an ECLIPSE approach

Expectation	Client Group	Location	Impact	Professionals	Service
To explore hospice organisational issues relating to the provision of services for people with dementia	Hospices	England	Hospice services for people with dementia	Hospice staff	Dementia
Alternative Words					
Palliative care	Palliative care	UK and Ireland	Palliative care	Palliative Care Nurses	Alzheimer's Disease
End-of-life			End-of-life	Palliative Medicine Consultants	
Institution			Service development		
Charity					
Culture					
Organisational change					

ECLIPSE proved a useful framework and in fact refined the research topic into: A mixed methods study exploring organisational factors influencing the development of services for people with dementia in English hospices’.

The questions and sub-questions are listed in Section 1.3. Using ECLIPSE to refine the research topic also helped formulate the search strategy, with the alternative words prompting searches. The literature search strategy and process is discussed in Section 3.1.

3.1 Literature search strategy

The literature search enabled the research to ‘be informed by and build on existing knowledge’ (Ritchie, et al., 2014, p. 51) and to ensure an understanding of existing perspectives and relevant topics and that this study did not duplicate work already undertaken. A literature search ‘identifies what the researcher takes to be the key issues, the crucial questions and the obvious gaps in the current state of knowledge’ and provides ‘signposts for the reader, about where the research is coming from’ (Denscombe, 1998, p. 158).

The literature search took place throughout the course of completing the thesis, however the bulk of the searches, the empirical search took place end of 2017/Spring 2018 and the applicability of dementia search took place first quarter of 2017.

A comprehensive literature search strategy was conducted which involved identifying relevant key terms and searching sources of data. Literature included books, articles, reports, websites and conference proceedings.

The literature review has been conducted in four parts which are presented in four sections within this chapter. And which are now introduced for clarity.

3.1.1 Historical literature

Historical literature to provide an overview of care of the dying and how it relates to dementia and cancer was explored to establish the context for research. This

section provides both depth and richness to help the reader understand and appreciate the institutional nature of hospice organisations that leads to their current form and identity. It will also provide a contemporary overview of the size and contribution of the hospice field of practice

For this category of literature, key texts were selected that were relevant to providing a historical overview of care of the dying relating to dementia and cancer including the formation of the hospice movement. The challenge was keeping to what was relevant in setting the scene. The researcher had insider knowledge of key texts such as those by David Clark (2003, 2016) and Shirley du Boulay (2007). Searching the Keele University Library, Google and Amazon resulted in additional books being sourced including Paul Rossi (2009) on Macmillan and several hospices books depicting their own history. The individual hospices history texts were excluded as whilst interesting did not contribute to the wider historical picture. Literature from a previous search undertaken for a taught professional doctorate module focusing on community and social care provided additional texts to add to the hospice focused texts. The key texts selected to provide the historical overview included:-

- Cicely Saunders : The founder of the modern hospice movement (Boulay, 2007)
- To Comfort Always : A history of palliative medicine since the nineteenth century (Clark, 2016 i)
- Fighting Cancer with more than medicine : A history of Macmillan cancer support (Rossi, 2009)
- "Waiting for the last summons" : The establishment of the first hospices in England 1878-1914 (Humphreys, 2001)
- The Five Giants: A biography of the welfare state (Timmins, 1996)
- Health Policy in Britain (Ham, 1999)
- The Local Right – Enabling not providing (Ridley, 1988)

The inclusion and exclusion criteria is summarised below:-

Inclusion: - known texts by leading authors in the field, known texts relating to community and social care, additional literature identified in the general search that added to the historical context.

Exclusion: - Individual hospice history books that didn't add to the wider context, international texts.

3.1.2 The relevance of hospice care for people with dementia

If hospice care is not relevant for people with dementia, then hospices would not need to provide services for this population. Therefore, discussing the relevance of hospice care is important in establishing the rationale, importance and contribution of this research.

This category required a systematic search of health databases. A comprehensive literature review was conducted via EBSCO, selecting all health databases; including AMED, MEDLINE, PsycINFO, AgeLine, CINAHL, PsycARTICLES, and Academic Search Complete.

The search strategy was limited to UK and Ireland studies in the English language with the key words being found in the abstract. Whilst the primary focus is on practice in England, searching for UK and Ireland was consistent with the ECLIPSE approach of alternative words to extend the search to ensure key texts were not overlooked. A further search was conducted via Keele Library database with search terms palliative care AND dementia (see table 3.2, page 66). A spreadsheet providing an overview of the complete search can be found in Appendix One (page 241). In addition to this search a European article known to the researcher was included 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care' (van der Steen, et al., 2013).

Table 3.2 – Search results for the relevance of hospice care for people with dementia

Stage of Search	Number of Articles
Full search results	521
Review of titles and abstracts (duplicates removed during this process)	25 (articles were imported into NVIVO and read)
Final search results	15 were relevant

Table 3.2 summaries the results found that were relevant for this topic. The inclusion and exclusion criteria is summarised below:-

Inclusion: - articles related to end of life care or palliative care or hospice AND dementia or Alzheimer's,

Exclusion: - international texts (other than van der Steen et al, 2013)

Section 3.1.3 discusses the search strategy for policy literature.

3.1.3 Policy literature

The policy environment can provide external influence into the discourse of hospice strategy. Government and legitimating agencies such as the Alzheimer's Society, Hospice UK, what was the National Council for Palliative care add to the policy debate. Therefore, an understanding of these influences can help further consideration of the impetus for change.

To explore the policy context relevant to the research, literature was identified from two sources:-

- a. Government sources and reports
- b. National bodies that are legitimating organisations (see section 3.4)
including:

- National Council for Palliative Care
- Hospice UK
- Alzheimer's Society
- Marie Curie

Several relevant reports were already recognised as important by the researcher:

- End-of-life Care Strategy, (DOH, 2008)
- My Life until the End: Dying Well with Dementia, Alzheimer's Society (2012)
- Dementia: State of the Nation, (DOH, 2013)
- Commission into the Future of Hospice Care, Hospice UK (2013)
- Living and Dying with Dementia in England: Barriers to Care, Marie Curie & Alzheimer's Society (2014)
- Hospice Enabled Dementia Care, Hospice UK (2015)

In addition, specific searches were undertaken, those on Google © and the DOH website resulted in a high number of results which were scanned to select relevant documents.

The inclusion and exclusion criteria is summarised below:-

Inclusion: - formal reports, meeting the relevant time frames that contributed to an understanding of the policy context

Exclusion: - policy literature outside of the timeframe, international policy

A list of documents included are in Appendix One (page 238).

Table 3.3: Policy Search Criteria

Search vehicle	Search Terms	Additional Relevant Reports

Keele Library	Author = National Council for Palliative Care AND subject = dementia	N/A
Keele Library	Author = NCPC AND subject = dementia	4
Keele Library	Author = Alzheimer's Society AND subject = palliative	N/A
Keele Library	Author = Marie Curie AND subject = dementia	N/A
Google and DOH	Palliative AND dementia AND policy End-of-life Care AND dementia AND policy Dementia AND policy David Cameron AND dementia challenge	12
Hospice UK website	Dementia Non-cancer	1

It is acknowledged that some of these publications are by campaigning organisations who might benefit from policy change and therefore are subject to bias.

3.1.4 Empirical literature

There is a paucity of literature on the organisational nature of hospices. Additionally, there is limited research on other service innovations or changes within hospices that reference organisational concepts. However, those that exist are discussed to add to the breadth and depth of this research. This section also highlights the gaps in current research relating to hospice organisations and factors relating to institutional change.

This category required a systematic search of health databases. A comprehensive literature review was conducted via EBSCO, selecting all health databases; including AMED, MEDLINE, PsycINFO, AgeLine, CINAHL, PsycARTICLES, and Academic Search Complete. In addition, a Keele Library

database and PROQUEST were reviewed to see if any alternative articles had not been discovered via EBSCO.

Search terms included a range of terms relating to hospices as organisations, dementia and end-of-life care (see Table 3.3, page 67). A spreadsheet providing an overview of the complete search can be found in Appendix One (page 244).

The 'alternative words' element of ECLIPSE (see table 3.1, page 62) enabled an iterative element to the search strategy, considering when there were gaps in literature what other terms might help find relevant and useful data.

The empirical literature was divided into four categories after the search in order to consider the type of data that was available:

- Organisational – empirical literature directly relevant to hospices as organisations. This also included studies that related to non-clinical aspects of hospice that had an organisational bias e.g. IT systems and HR
- Dementia – literature directly related to dementia, palliative care and hospice organisations
- Non-malignant disease – literature related to other conditions that also discussed organisational or institutional factors

The full search is in Appendix One (page 244), broad inclusion and exclusion criteria is summarised below:-

Inclusion: - articles relating to studies in hospices that had an organisational or institutional context, palliative care service developments, articles relating to culture or identity, studies of other disease service development in palliative care or hospice that provide organisational insight

Exclusion: - international studies, studies not relating to hospice or palliative care organisational aspects (for example NHS studies)

Table 3.4 – Search results for empirical literature (hospices as organisations)

Stage of Search	Number of Articles
Full search results	450
Review of titles and abstracts (duplicates removed during this process)	43 (articles were imported into NVIVO and read)
Final search results	15 were relevant for this literature category, and 4 applied to other categories and incorporated accordingly

Table 3.4 shows the search results for this category of literature. It also shows how any articles that emerged from this search were incorporated to other categories as appropriate.

Section 3.1 has described the search strategy, Section 3.2 will discuss the literature in detail starting with the historical context.

3.2 The historical context

To tell the story of the hospice movement, key texts including Shirley Du Boulay's biography of Cicely Saunders (Boulay, 2007), David Clark's book 'To Comfort Always' (Clark, 2016 i) and Paul Rossi's book on the history of Macmillan (Rossi, 2009) were selected. The story has been well told, however, the aim of this narrative is to provide the social context within which hospice care originated. The narrative recognises the individual journey of individual hospices and the movement itself which creates the distinctive identity that develops over time as

the process of institutionalisation take place (Suddaby & Greenwood, 2009, Selznick, 1957).

The creation of the hospice movement was in direct response to how people with terminal cancer were being cared for. Contrasting the cancer story with the alternative for dementia is instructive and helps explain why, with the demographic changes that the country is now facing, the contexts for these two disease categories have collided.

This section contains eight sub sections representing themes from the literature review: care of the dying, dementia care, cancer care, and the creation of the hospice movement, Dame Cicely Saunders and St Christopher's Hospice, the modern hospice movement, dementia care and hospice care today. This approach takes the reader on a journey to understand the historical context that is part of the narrative and identity of hospice care today.

3.2.1 Care of the dying

Care of the dying appeared in the medical literature in the early 19th Century with key texts by Carl Friedrich Heinrich Marx (*De Euthanasia Medica* presented in 1826), Hugh Noble's thesis in 1854 and Dr William Munk's 'Euthanasia – or Medical Treatment in Aid of an Easy Death' published in 1887 (Clark 2016).

Care for people during the 19th Century was based on the social class with people with higher incomes being nursed at home. For the 'deserving poor' there were voluntary hospitals, although people dying were not always welcome and for the 'undeserving poor' there were the workhouse infirmaries (Humphreys, 2001). There was no consistent approach to care.

The 19th Century saw the building of institutions and hospitals that Clark (2016) describes as 'the new citadels of care and the sites of medical professionalization and academic respectability' (Clark, 2016 i, p. 34). 'By the early 1880s, institutions existed for virtually all forms of treatable and curable conditions, and even for incurable and chronic patients' (Humphreys, 2001, p. 153). People who

were terminally ill or dying were often excluded from these institutions and there became a space for homes for the dying and the creation of what Humphreys (2001) describes as 'the first institutional provision in the British Isles specifically for the dying poor' (Humphreys, 2001, p. 146). A reporter in the 'Contemporary Review' of March 1891 wrote that 'there is not to be found any refuge, home, or hospital but the workhouse for the man who is neither curable nor incurable, but actually dying' (Clark, 2016 i, p. 35). From Section 3.1.2 onwards will segment the literature into dementia and cancer.

3.2.2 Dementia

This section will outline history that is relevant to dementia care. It will cover some of the changes in government policy from workhouses to non-residential community care. This section will focus on policy decisions relating to the care of older people. Whilst there are people affected by young onset dementia, there is a higher prevalence of the disease in older people (Alzheimer's Society, n.d. i).

The symptoms of what we now know as dementia are not a new phenomenon (Boller & Forbes, 1998). The term dementia according to Berrios (1987) was recognised from 1670 although the term appeared in various publications from the 14th Century. In the 19th Century there were only two options for people with dementia, either care at home with family and informal community help, or if this was not possible admission to a lunatic asylum. As charitable homes for older people and workhouses were less equipped to care for people who wandered or who had behavioural issues, lunatic asylums were often the only option for people with dementia. However, as the asylums reached capacity, referral criteria were increasingly restricted, people with senile dementia were sometimes excluded people who could not be cured (Andrews, 2014).

The establishment of the NHS in 1948 resulted in many workhouses becoming public hospitals and being transferred under their new and emerging structures from 1948 (History Extra, 2010). Many of the residents were elderly and unable

to be cared for after anywhere else. The Seebohm Report (1947) recommended the development of smaller residential homes and The Royal Commission on the Law Relating to Mental Illness and Mental Deficiency (1957) recommended that people should be cared for in the community rather than in institutions, however, this took time to achieve.

During the 1980's, an NHS funding crisis raised concerns about the increasing numbers of older people as patients and in society generally (Ham, 1999). Ridley (1988) who had contributed to Margaret Thatcher's government policy of de-nationalisation, recognised the growing numbers of older people and recommended again increasing care in the community. Ridley suggests that there were a whole range of agencies able to provide services and stated that it was 'sentimentality to argue that therefore they should be exempt from the same disciplines of competition and value for money as other parts of the public sector' (Ridley, 1988, p. 18). So, the debates about place of care continued.

Griffiths (1988) described community care as 'a poor relation; everybody's distant relative but nobody's baby' cited by (Timmins, 1996). Community Care includes all care delivered outside hospital including homecare, district nursing, meals on wheels a combination of what today is described as healthcare in the community (i.e. district nursing) and social care (i.e. homecare services). Griffiths' key question was 'who should be in charge?' (Timmins, 1996, p 473) of community care between either health authorities, local authorities or some new entity. The Community Care Act (1990), which followed Griffiths' report (1988), resulted in Local Authorities being responsible for the commissioning, but not the provision of social care maintaining a difference between means tested social care and free NHS care. For people living with dementia, as per today, their care would have been means tested and the options being care at home or if this was not possible, a place in a residential care home.

The care for people with dementia was caught between shifts in policy with a focus on increased community care, the closure of traditional institutions, increased reliance on private sector social care organisations and new smaller residential care facilities. The development of care for people with dementia during this same time period, varies considerably in comparison to the care for people with cancer. This history is told in more detail as this builds the historical narrative of the modern hospice movement.

3.2.3 Cancer

This section aims to outline the historical context that influenced the formation of hospice and its relationship to cancer as the disease that dominates its care provision. Cancer, like dementia is not a modern illness, there are dinosaur fossils with evidence of cancer and various references to it throughout history. The first dedicated cancer ward was opened at Middlesex Hospital in 1792 (Rossi, 2009). In the 18th Century medicine was developing rapidly, improved surgical techniques, anaesthesia and the use of radium all impacting the range of treatments for people with cancer. However, treatment and care were not universally available.

Specialist cancer charities were formed to support prevention, treatment and care, including the Imperial Cancer Research Fund in 1902, The National Society for the Prevention and Relief of Cancer (later renamed Macmillan Cancer Support) established by Douglas Macmillan in 1911, The Cancer Research Campaign in 1923 and Marie Curie Cancer Care in 1948 (Rossi, 2009). Douglas Macmillan's early work included publishing statistics of cancer prevalence in the UK. He showed how the prevalence of cancer would increase and stated in 1910 that 'In five years' time cancer will have outstripped its rival and will have a heavier death toll than consumption.... and rides rough-shod over the whole realm of medical ingenuity' (Rossi, 2009, p. 43) and in 1930 he wrote that 'there died from cancer in England and Wales no fewer than 57,833 persons, or three

times the total number of deaths occurring on both sides in the whole course of the Boer War' (Rossi, 2009, p. 71).

Rossi suggests that Macmillan highlighted the lack of capacity in hospitals for people with cancer. In the years running up to the formation of the NHS, there were a few specialist cancer hospitals and some voluntary hospitals with specialist wards, however, there was a focus on cure, treatment and short-term care. For people needing longer term care there were the public hospitals run by local authorities, or the infirmaries within what was left of the workhouses (Rossi, 2009). Convalescent homes were formed in the mid-19th Century in the recognition that patients could move from an acute hospital to an alternative setting. (Lost Hospitals of London, n.d.). Care at home was variable with District Nursing Services growing and some charitable provision.

The Cancer Act (1939) required local authorities to develop and present plans that ensured services were available for the diagnosis and treatment of cancer, the Act also focused on diagnosis and treatment, it did not provide for people who were not curable (Rossi, 2009).

In 1931 Douglas Macmillan's vision was to see a 'chain of homes for cancer patients throughout the land...the poorest people to be provided with the latest and best advice...panels of voluntary nurses who can be detailed off to attend to necessitous patients in their own homes' (Rossi, 2009, p. 74). However, Rossi (2009) suggests that progress on improving care was stalled during World War II as attention and funding was diverted.

The stories of care for people dying with cancer at this stage are so intertwined with that of hospice care that it will be continued in Section 3.2.4 relating to the creation of the hospice movement.

3.2.4 The creation of the hospice movement

The story of the origins of the hospice movement has been told many times (Boulay, 2007; Clark, et al., 2005; Humphreys, 2001). This chapter does not aim to replicate or do justice to the telling of the movements history but aims to summarise early history leading onto the formation of St Christopher's which opened in 1967 and is recognised as the founding 'modern hospice'.

The first home for people dying in England, 'the Friedenheim' (translates in German to peace and home) was founded by Frances Davidson in 1885 who had worked with a Mission Hospital in the East End of London. Davidson had an interest in creating a home of peace for people who are dying and had been inspired by the fate of people with tuberculosis. (Clark, 2014). Demand outstripped the capacity and following a campaign a larger Friedenheim was opened in 1892 with the word hospital being added in 1899. In 1915 its name was changed to St Columba's Hospital. The Hospital joined the NHS in 1948 and closed in 1981. (ezitis.myzen, n.d.). Unlike other early hospices such as St Joseph's in London and John Taylor Hospice in Birmingham, the Friedenheim did not develop into a 'modern hospice'. However, when the London East End hospital St Columba's Hospital closed, the situation for local people was found to be unacceptable. Local GP Dr Chris Hindley started a working group to create The North London Hospice which opened as a multi-faith community-based service in 1984. (North London Hospice, n.d.).

In addition to the Friedenheim, other early homes for the dying include: -

- Hostel of God, Clapham, London 1891
- St Luke's House, Regents Park, London 1893
- St Joseph's Hospice, Hackney, London 1905
- Home of the Compassion of Jesus, Deptford, London 1903

(Humphreys, 2001).

Humphreys (2001) and Clark (2016) describe the influence of religion in these homes and the focus on 'conversion' as people prepare for their death and the acceptance of pain and suffering as being part of 'gods will'. These early homes were also for the 'respectable and deserving poor'. Humphreys (2001) cites a passage from St Luke's Annual Reports 'the unworthy poor must be treated and provided for differently' (Humphreys, 2001, p. 160).

Another early hospice was the John Taylor Memorial Home (now John Taylor Hospice) in Birmingham that claims to be the 'oldest non-denominational hospice in the UK, opening in 1910. (John Taylor Hospice, n.d.). These early homes for the dying do not appear to have worked together in any capacity (Clark, 2016 i; Humphreys, 2001).

Alongside the rise of care institutions in the 19th Century and the lack of provision for people who were dying both in the voluntary hospitals and in community based care, these homes were established as an 'institutional response to a domestic problem' (Humphreys, 2001, p. 153). As per disease prevalence at the time, most of the patients admitted during this late Victorian/Edwardian era were suffering from tuberculosis.

Clearly the outbreak of war and the negotiations leading to the formation of the NHS will have impacted progress. Clark (2016) describes this period in the development of hospice and palliative care as 'indifference'. The homes did not influence healthcare more broadly, medicine was not focused on the care of the dying, the early work of the 'grandfather of palliative medicine' is perhaps

forgotten and knowledge is lacking. However, disease was also changing in the early 20th Century as prevalence of cancer took over from tuberculosis (Rossi, 2009) which must have challenged the knowledgebase of these early homes, awareness was growing that change was needed (Clark, 2016 i).

3.2.5 Dame Cicely Saunders and St Christopher's Hospice

This section not only provides insight into the development of the hospice movement but also introduces key practices and beliefs behind the developing cultural norms that contributed to the value that hospices were developing in their community.

Cicely Saunders was trained as a nurse, almoner (social worker) and then trained as a doctor. Her idea for a 'hospice' developed over time, with key moments described by Du Boulay (2007). Whilst volunteering at St Luke's House, Dame Cicely Saunders was introduced to a model of care that truly focused on the individual in addition to an alternative way of managing pain. St Luke's had developed a regular giving of pain relief in 1935 which had not been shared externally (Boulay, 2007).

In 1958, when Cicely Saunders started working with St Joseph's Hospice, she introduced the regular giving of pain relief she'd experienced at St Luke's. This enabled patients to be more alert and able to be themselves rather than being comatose (Boulay, 2007). Cicely Saunders's approach to care of the dying which later became a specialist field drew from her experiences as a nurse, almoner, doctor and her religious beliefs. This combination no doubt contributed to what is now called 'holistic care'.

Marx wrote in 1826 about some physicians 'with no shining ray of hope remaining, consider it their more lofty duty to lay to peaceful rest a life they can no longer save. Accordingly they will extend their energy and their affection, they will follow each successive turn of events, they will apply palliatives wherever they can, and with an all-caring heart they will put themselves in readiness for the

great event, so that the last breath of their passing may be light and not dreadful to those left behind' (Clark, 2016 i, p. 12). This is very much consistent with the ethos of care practiced by Cicely Saunders and her concept of 'total pain'. (Clark, 2016 i, Boulay, 2007). A patient, Mrs Hinson reportedly said to Cicely Saunders that 'all of me is wrong' and talked of her family concerns and her own psychological wellbeing alongside her physical pain (Clark, 2016 i). Cicely Saunders stated that 'pain demands the same analysis and consideration as an illness itself. It is the syndromes of pain rather than the syndromes of disease with which we are concerned' (Clark, 2016 i, p. 133). The concept of 'holistic care' and 'total pain' remain part of the narrative and distinctive identity of hospice care and contemporary palliative care in the UK.

During an era of changing public policy, an evolving welfare state, the new NHS and the challenges faced by government to meet the needs of the population, Cicely Saunders continued to develop her plan for a 'hospice'. This plan was to demonstrate to the NHS how to provide a different kind of care for people with terminal illness and to do this via a new charity and a hospice. From 1959 onwards, detailed memoranda presenting 'the need and 'the scheme' were circulated to likely advisers and supporters' (Boulay, 2007, Saunders, 2001).

Du Boulay (2007) cites Cicely Saunders in describing her relationship with the NHS 'We want to be independent because we need freedom of thought and action' she recognised however, the need to be part of the health economy and wanting contractual arrangements with the NHS to fund care. This view is consistent with current discourse within the hospice movement. In part, the desire to remain outside of the NHS is for the same reasons i.e. independence and freedom, however, institutional theory also considers the sustainability or an organisational field, the ongoing relationship with the NHS provides legitimacy and resources for hospices within their local health economy.

Du Boulay (2007) and Clark (2016) describe Cicely Saunders's internal battle regarding the extent to which her home should be a religious institution. This was settled by Rosetta Burch an almoner who said, 'to the outside world you must be first and foremost a medical concern... you are a Christian doctor not a spiritual leader with a medical vision' (Clark, 2016 i, p.92). Her vision combined spirituality with the very best medical and nursing care, but she accepted that to attract funding and possibly legitimacy within the healthcare industry she needed to be accepted as a medical organisation. She decided that religion would not be a factor when it came to admission and that religious conversion would not be expected. (Boulay, 2007). This was a critical decision in the future of the modern hospice movement. Given the power and institutionalised nature of the medical profession, it is hard to see how hospices would have gained wider influence and acceptance medically if spiritual leadership came before medicine. St Christopher's Hospice opened in 1967.

Dame Cicely Saunders was an extraordinary institutional entrepreneur driving social action and creating a new model of care, new organisational form and inspiring the development of a new institutional field. There was no equivalent for the care of people dying with dementia. However, the prevalence, visibility and demand for change may not have been comparable at the time i.e. the visible suffering was for people with cancer and people with dementia were hidden from society and less prevalent at that time.

3.2.6 The modern hospice movement

'Modern hospice care was developed in the sixties as a response to appalling deficits in care of those coming to the end of their lives and the neglect of those close to them' (Help the Hospices, 2013). St Christopher's focus on three specific areas of practice; clinical care, education and research set it apart from the early homes for the dying (Clark, 2016 i).

Du Boulay (2007) purports that Cicely Saunders did not intend to start a movement she wanted her model of care to move into mainstream provisions. She was surprised how her ideas spread and grew stating when questioned that she was 'the right person, in the right place at the right time' (Boulay, 2007, p. 180). Her reflections on a focus on buildings being a barrier to palliative care as a philosophy are interesting (Saunders, 2001) as it is a comment also heard today and is perhaps part of the challenge of institutional change.

As hospices developed, groups of professionals started to emerge from across the network of hospices and national organisations started to be established. This was inevitable as medicine was developing, professions forming and the specialisation of medicine emerging (Clark, 2016 i). Leading physicians were starting to consider how to train future generations in palliative care whether that be GP's, hospital or hospice doctors. However, there were questions about how to maintain the holistic nature of hospice care alongside the increasing professionalisation and specialisation. The Association of Palliative Medicine was established in 1985 and Palliative Medicine was accepted as a medical specialty in 1987 thereby enabling specialist training programmes and the development of Palliative Medicine Consultants (Clark, 2016 i).

The move to specialisation did raise some questions and Clark (2016) describes how for some it was about integration and perhaps acknowledgement and recognition alongside other mainstream disciplines. Others felt that the specialisation narrowed the holistic nature of hospice care and that the focus became primarily on physical symptoms, losing the concept of 'total pain' that Cicely Saunders advocated. There is also a perception that palliative care is the responsibility of all doctors and was 'generalist' in nature rather than requiring specialisation (Clark, 2016 i). There are some strong views on the subject for example 'the integration of the palliative care approach into everyday practice, and into the management of all patients with incurable disease from diagnosis to

death, has been an aim of the hospice movement from its early days and has lately been declared more vigorously. The specialist disease-specific model of palliative care depends upon the separation of this function' (Fordham, et al., 1998, p. 571). The specialisation of palliative medicine and the impact on hospice care was a significant 'jolt' creating change in the institutional history of the movement. This was a key moment in the history of hospice and was part of the organisational field developing, configuring and professionalising and starting to consider what type of care was legitimate. Dementia historically belonged to the field of mental health and older people, not specialist palliative medicine. The discourse around whether the 'specialisation of palliative medicine' was a positive change or created a barrier to care and the impact on hospice care continues today.

The growth of hospices in the UK accelerated in the 1970s peaking in the early/mid 1980s, with 61 hospices being formed in one five year period. Founders were a mix of local community members, healthcare professionals and religious leaders. For example, St Giles Hospice was founded by Reverend Paul Brothwell. He heard Cicely Saunders speak when on a clinical theologian course at St Georges Hospital in London. Brothwell had planned to be a parish priest but was being encouraged to consider hospital work and pastoral theology. Working as a parish priest in Whittington, near Lichfield, Staffordshire, he had a good relationship with the local GP and District Nurse and they would work closely together in the village. Brothwell was angered by the common phrase of the time 'there's nothing more we can do' and started to think about what a local response could be. Various debates relating to the future of the vicarage resulted in a decision to build a hospice. He rallied support around the idea gathering local support and a committee was subsequently formed. St Giles Hospice opened in 1983 as a response to care for people with cancer. Brothwell went on to work with the chaplain at St Christopher's Hospice to form the Association of Hospice Chaplains (Brothwell, 2016). Paul Brothwell, and many of

the hospice founders, were, like Dame Cicely Saunders incredible institutional entrepreneurs and part of the history of the hospice movement.

3.2.7 Hospice care today

Hospice care has grown significantly over its fifty-year history. Hospice UK produced a report in 2016 to provide an overview of hospice's care ahead of undertaking further work leading on national hospice datasets.

The Hospice UK report (2016) with the aim of presenting a national dataset estimates the following, for charitable hospice care:

Table 3.5 – Hospice care today in numbers (HUK, 2016)

'People accessing hospice care	200,000
People receiving inpatient care	48,000
Beds in inpatient hospices	2,760
Percentage of people returning home after receiving inpatient care	32%
People seen by community-based nursing teams (including healthcare assistants)	159,000
Number of community/home visits	948,000
Number of people receiving bereavement support	41,000
People seen in day hospice	35,000
Statutory contribution to adult hospice care	33%
Spend on charitable hospice activity	£868 million'

(Hospice UK, 2016).

The hospice movement, as an organisational field, has grown into a significant provider of specialist healthcare and remained independent, primarily community funded organisations. However, the discourse within the hospice movement by individual organisations, by Hospice UK and by parts of the NHS is questioning the ongoing cancer dominance. The motivation of this challenge appears to be one of equity and therefore has moral foundations, but raises issues of financial sustainability and legitimacy both in terms of the local community who generate the majority of funding and by NHS commissioners.

Contemporary dementia care

Seventy percent of people living in care homes have dementia (Alzheimer's Society, n.d. i), their residents experience significant issues in relation to access to NHS services at the detriment to their well-being. The Alzheimer's Society report that people with dementia are being treated like 'second class citizens' leading to 'people with dementia being bed-bound, incontinent and sedated' (Alzheimer's Society, 2016, p. 12). Twenty-five percent of patients on acute hospital wards have dementia (Dementia Action Alliance and Institute for Innovation and Improvement, n.d., p. 3), a hospital admission is often seen as the only solution to a crisis whether that be a medical or social issue. A hospital admission for someone with dementia can be a distressing and disorientating experience (Marie Curie, 2009). It seems that despite all of the policy changes community care, including for people with dementia, remains 'a poor relation; everybody's distant relative but nobody's baby' (Griffiths, 1998, cited by Timmins, 1996). There have been attempts to raise the profile of the needs for people with dementia which will be discussed in Section 3.4.

England has a higher rate of hospital deaths for people with dementia than most of Europe – research in 2014 identified that two out of every five people with dementia die in hospital (Sleeman, et al., 2014). Most people with dementia die in care homes, few patients die at home and even less in hospices. A 2014

study (Sleeman, et al., 2014) suggests that a home/hospice death was more likely in an affluent area and for those with cancer as the underlying cause of death. Families of people dying in hospital describe poor care planning and inadequate symptom control for issues such as pain and breathlessness (Bayer, 2006). Sampson et al. (2011) criticise the end-of-life care strategy for not emphasising enough the growing issue of people dying with dementia and equally criticise the national dementia policy for not sufficiently highlighting the issue of end-of-life care. These policy documents are ways of influencing the field of practice, be that palliative, dementia or any other relevant field. The lack of priority given to end-of-life care for people with dementia in these documents does little to highlight the need for a change in service provision.

Dying without Dignity (2010), highlights half of all NHS complaints relate to end-of-life care (Leadbeater & Garber, 2010, p. 14). Whilst not specifically relating to dementia, there is nothing in the literature to suggest that dying with dementia is better than any other condition and if anything is worse (Bayer, 2006, Sampson, et al., 2011, 2018, Marie Curie, Alzheimer's Society, 2015).

Bayer says that it 'is exceptional' for any of the 100,000 people who die in the UK with dementia each year to die in a hospice and 'unusual' for any formal involvement of palliative care services (Bayer, 2006, p. 101). Despite there being similarities in the symptom burden between people with advanced dementia and people with cancer, 'futile and distressing admissions to acute hospital' for issues such as pneumonia or infections are the most common cause of death.

(Sampson, et al., 2011, p. 357). This would indicate that there are at least similarities in the physical care for these two different categories of people.

Sampson et al. (2011) suggest that the lack of capacity for decision making of people with dementia, in comparison to people with cancer has a significant impact on the provision of good quality end-of-life care.

Marie Curie and the Alzheimer's Society report a growing evidence that in comparison to people with other terminal diseases that people with dementia are a) not being appropriately identified for end-of-life care, b) have less access to end-of-life care services and c) receive poorer quality of care. (Marie Curie, Alzheimer's Society, 2014). This view is also represented in a study by Ryan et al. (2011) which gathered opinions of healthcare professionals on the barriers and facilitators relating to palliative care for people with dementia. This call for equality is in keeping with Linda McEnhill's view on human rights articulated in the Hospice Enabled Dementia Care report (Hospice UK, 2015).

This literature has provide a historical and contemporary narrative related to care of the dying for people with cancer and people with dementia. The literature demonstrates that there are significant discrepancies between how people with these diseases are supported. There is no hospice equivalent for people with dementia and hospices history is steeped in cancer. The literature highlights the tensions around equality of access, some of the perceived differences between the needs of people with dementia and those cared for by hospices. There are deficits in care for people with dementia and the literature is unclear about how these needs will be met.

The following section will explore the literature relating to hospice care and dementia. Just because a disease is prevalent does not mean that the institutional field of hospice care has to respond to it. For dementia to be the 'jolt' that this research is suggesting, there needs to an argument that the hospice movement *should* respond.

3.3 The relevance of hospice care for people with dementia.

To address the question regarding hospice services for people with dementia it is first necessary to demonstrate relevance. For example, if dementia was not a palliative illness then care might fall outside the remit of hospice organisations. Without addressing this issue, the question of how hospices could, have or

should respond is completely hypothetical. In addition, it is necessary to argue that improvements in dementia care are needed, i.e. if there are no issues then there would be no imperative to act. The focus of the search was to find articles discussing the relevance of hospice or palliative care for people with dementia.

There is a growing evidence base relating to palliative care for people with dementia including recognition that dementia is a terminal illness and the benefits of palliative care (Van der Steen et al., 2013, Ryan et al., 2011, Davies et al. 2014, Marie Curie, Alzheimer's Society, 2015). Van der Steen (2013) conducted a Delphi study with the aim of defining optimal palliative care for people with dementia. The study consisted of five rounds with a core group of twelve experts across six countries although there was input from sixty-four experts across twenty-three countries and the European Association of Palliative Care Board. Experts were drawn from the field of dementia and palliative care. This study reviewed relevant literature including empirical studies and policy reports.

Full consensus was achieved based on the conceptual question of 'With regard to care and treatment, I feel that palliative care is important in older people with Alzheimer's disease and other progressive dementias' (van der Steen, et al., 2013, p. 205) There was no consensus reached on whether palliative care was more or less important in different levels of severity of dementia, although low disagreement of applicability only for severe dementia.

The WHO (2015) definition defines palliative care as applicable to 'life threatening illnesses', from a simplistic perspective, dementia fits i.e. there is no cure and people do die from dementia. However, dementia is under-recognised as a terminal condition impacting access to care (Van der Steen, et al., 2013, Ryan, et al., 2011, Amador, et al., 2016) suggesting a growing recognition by clinicians and policy makers of the importance of palliative care for people with dementia.

There are similarities in the physical problems of people with advanced dementia and those with cancer e.g. pain and the symptom burden is comparable.

However, symptoms for people with dementia are often under diagnosed and under treated (Sampson, et al., 2011, 2018).

However, there is then a further question as to whether dementia requires specialist palliative care i.e. is there complexity that requires input from teams with specialist training. Ryan et al. (2011) heard views in their study that dementia was less worthy than other conditions when it came to specialist palliative care. Sampson et al. (2011) questions the applicability of hospice care to people with dementia providing an alternative argument to the claim that 'people are denied access to hospice care' highlighting that hospices focus on specialist need and that the needs of people with dementia 'do not require specialist palliative care intervention but good quality basic care'. (Sampson, et al., 2011, p. 358). Whether hospices are providing specialist palliative care, palliative care, or end-of-life care does come back to identity, definitions, understanding and the developing strategy of both individual hospices and the hospice movement.

In conclusion the literature is consistent regarding the applicability of palliative care for people with dementia, however, the applicability of specialist palliative care is not sufficiently addressed. This opens up the question of the distinctive identity of hospices, if hospices norms, values and beliefs and their concept of legitimacy are aligned to specialist palliative care then perhaps care for people with dementia is less of a 'jolt' and is a discussion on the boundaries rather than a call for institutional change.

Section summary

In outlining the need for this research in Chapter One, it was important to demonstrate that hospice care was relevant to the field of dementia and that improvements in end-of-life care were required. If it was perceived that dementia

did not require the services of hospices, then the research would be hypothetical and of little value. The literature is convincing in the applicability of palliative care for people with dementia and convincing of the need to improve care for people with dementia validating the need for this research. The literature also leaves areas that are not addressed such as whether the services are of a generalist or specialist nature.

The institutional story of hospice organisations has not previously coincided with that of dementia. The growing number of publications highlighting the applicability of palliative care for people with dementia alongside the deficits in care adds to the external factors creating the tension and growing interaction between these previously disconnected fields.

The next section will consider policy literature related to dementia.

3.4 Policy literature related to dementia care at end-of-life

This section will include key documents from three legitimating organisations that influence hospice; the Department of Health, the National Council for Palliative Care and Hospice UK. These organisations do not necessarily have equal status as legitimating organisations however, all have influence over organisational direction, professional and public opinion and resources. Legitimating organisations can provide legitimacy by mechanisms such as membership or compliance, Trank and Washington (2009) write that these organisations are often 'the public vehicle and symbolic touchstone' and that they are often the 'focal and public face of complex institutional arrangements' (Trank & Washington, 2009, p. 236). In addition, reports from other key organisations such as Alzheimer's Society and Dementia UK will be referenced.

Literature from a ten-year period from 2007-2017 has been identified for review.

This period of time was selected as it covered three relevant points in time: -

- i. The publication of the Government's End-of-life Care Strategy (DOH, 2008)
- ii. The Prime Minister's Dementia Challenge in 2012 (DOH, 2012)
- iii. Hospice UK's Hospice Enabled Dementia Care publication (Hospice UK, 2015)

2012 was a pivotal date in policy profile for people with dementia and therefore this chapter will be split into two-time periods; 2007-2011 and 2012 onwards.

3.4.1 Part one - 2007-2011

Hospice UK (then known as Help the Hospices) had acknowledged the need for hospices to widen access to a greater range of diseases. They launched a Care Beyond Cancer Programme in 2004 to support hospices in developing alternative services and models of care, none of these projects were for people with dementia although one of the 20 supported projects focused on care for older people (Help the Hospices, 2007). Grant giving programmes are a way that a legitimating organisation can influence direction, i.e. in this case providing resource for projects challenging the norms of cancer dominance. Hospice UK continues to provide grant funding for specific areas of care.

The National Council for Palliative Care (NCPC) was until 2017 (when it merged with Hospice UK) a membership-based charity for people involved in the provision or commissioning of palliative care, including NHS organisations and hospices. NCPC produced a series of reports between 2006 and 2009 relating to palliative care for people with dementia. These reports were not produced in collaboration with Hospice UK which suggests fragmentation between two meta-organisations operating in the field of hospice care. NCPC was a membership organisation for anyone involved in palliative care, including NHS organisations rather than just for hospices. In reviewing these reports, it is clear NCPC

advocated access to palliative care for people with dementia and provide some practical, clinical detail about both similarities and differences of care needs.

NCPC acknowledge the government policy and discourse relating to palliative care for people with dementia and comment on specialist palliative care being focused on people with cancer. NCPC are clear in the applicability of palliative care for people with dementia whilst raising the question of appropriate care models and not replicating the care designed for people with cancer (NCPC, 2006).

‘NCPC’s latest work shows that there has been little development within existing specialist services and progress with other models of shared care to meet the palliative and end-of-life care needs of people with dementia. Policies or specific clinical practices related to palliative care for people with dementia appear to be very limited’. (NCPC, 2007, p. 8).

There is recognition in the 2007 report that some specialist palliative care services are involved with people with dementia but only when they also have another terminal illness such as cancer. The report also acknowledged what is described as ‘short bursts of training by hospice and specialised nurses’ in care homes (NCPC, 2007, p. 17).

The NCPC’s 2008 report suggests some progress, publishing case studies of several examples of palliative care for people with dementia three of which refer to hospice input as part of a Palliative Care in Dementia Group, the hospices being Sue Ryder Thorpe Hall Hospice, St Christopher’s and St Oswald’s. The report outlines some discussion points relating to partnership working and issues such as ‘nervousness of taking on a large new client group’, the impact on existing core services, ‘reluctance at moving out outside their comfort zone’ and funding pressures (NCPC, 2008, p. 35). In 2009 NCPC summarises the issue of specialist palliative care and states ‘the traditional model of palliative care based

largely around specialist palliative care and hospices is probably not appropriate for people with dementia' (NCPC, 2009).

The report provides a case study of a lady with dementia who was then diagnosed with cancer, the hospice and the local palliative care team both said they could not provide care for her due to her primary diagnosis of dementia. The lady was admitted via A & E and died within 8 hours. The report states that 'people with dementia require the same care as other patients towards the end-of-life but too often they fail to access support from palliative care teams and hospices' (NCPC, 2009, p. 8) suggesting that this is due to the difficulty in assessment and a lack of skills. The reports are challenging the norms of hospice and using emotive stories to do so in an attempt presumably to create a shift in direction by palliative and hospice care providers.

A further report also published in 2009 by NCPC in partnership with the Alzheimer's Society and For Dementia comments that whilst palliative care services have moved beyond cancer, people with dementia are not frequently referred to or cared for by these services. It states that this 'is surprising as dementia is a condition whose prognosis overlaps many of the conditions already seen by palliative care services' (NCPC, For Dementia and Alzheimer's Society, 2009, p. 4). It references hospices specifically 'hospices may find it difficult to manage challenging behavioural symptoms, especially in mobile patients needing respite. However, inpatient palliative care could be a realistic alternative to hospital admissions for short-term acute medical crises in advanced dementia, but not for regular respite' (NCPC, For Dementia and Alzheimer's Society, 2009, p. 5). In advocating for a partnership approach between dementia and palliative care services, several references are made to hospices. The report suggests that due to higher staffing ratios and a high-quality environment, that hospices should be a viable alternative to a hospital admission but then goes on to suggest this is unlikely due to continuity of care in other settings reducing distress, safety

issues in a hospice environment, staff confidence in dealing with behavioural problems and competition for hospice places (NCPC, For Dementia and Alzheimer's Society, 2009).

This is a confusing combination of statements and perhaps demonstrates the varied discourse around appropriate models of care. On one side there are the benefits of high-quality care, increased staffing and better environments in comparison to alternative inpatient settings and on the other side there are issues of continuity of care, change of environment, confidence and skills of the hospice workforce. This fragmented discourse provides no clarity or roadmap for hospices. It does nothing to contribute to a legitimate argument in either direction i.e. to provide services or not to.

NCPC at times represent quite a narrow interpretation of hospice care and a focus on inpatient settings. The suggestion that specialist palliative care services may not be transferable to dementia and that the suggested input for hospices relates specifically to inpatient care is not consistent with hospice services at that time but based on beliefs and assumptions, i.e. the perceived institutional narrative around the boundaries of hospice care. Many of the challenges within the reports are relevant and consistent with later literature from the hospice sector.

NCPC changed strategy from publications to hosting national conferences, these could be classed as 'field configuring events' (Hardy & Maguire, 2010). Field configuring events are mechanisms where new narratives can be told in order to challenge the status quo and influence change (Hardy & Maguire, 2010). The National Clinical Director for Dementia, Professor Alistair Burns presented and challenged the audience to consider end-of-life care (NCPC, 2014). They also established, (with the Alzheimer's Society) an All Parliamentary Group on Hospice, Palliative Care and Dementia which first met in July 2011 (NCPC, n.d.).

From a UK government perspective, prior to the first national dementia strategy being published in 2009, there were some policy documents relating to dementia indirectly e.g. as part of an older people's strategy. For example, the National Service Framework for Older People (DOH, 2001) set as a priority the identification of older people requiring palliative care recognising that palliative care has been focused on people with cancer. The framework also calls for improvements in services for people with dementia. The 2006 Living Well in Later Life report (Commission for Healthcare Audit and Inspection, 2006) also refers to improved supportive and palliative care in later life.

In 2008 the DOH published the End-of-life Care Strategy (DOH, 2008). This policy document called for improvement in care and comments on the variation between hospice deaths for people with cancer in comparison to other illnesses. The strategy proposed that the future of hospices will include improved access for patients with non-malignant disease and that this is unlikely to be a bed-based model. The strategy does comment on the requirement for adequate funding. This is an example of a national organisation providing an opinion on the future of hospice care, challenging the norms around cancer dominance within hospices.

The first major policy document specifically on dementia was 'Living Well with Dementia: A National Dementia Strategy' (2009). This policy document set an objective for improved end-of-life care for people with dementia and the suggestion to liaise with and utilise palliative care networks and providers. The strategy referenced a report by Sachs et al. (2004) that summarised the inadequacy of care as 'people with dementia often die with inadequate pain control, with feeding tubes in place, and without the benefits of hospice care' (DOH, 2009). This is a further example of national influence on hospice strategy.

There was a flurry of government documents on dementia leading up to 2012 in fact there are twenty links to letters, videos and publications listed on the government's policy website. In searching each of these publications there was

limited reference to hospice, palliative care. There are some references to end-of-life care i.e. an aim listed in a DOH quality outcomes publication 'I am confident my end-of-life wishes will be respected. I can expect a good death' (DOH, 2010, p. 12). There is a clear focus on increasing the diagnosis of people with dementia and investment in this area (DOH, 2010) rather than on issues to do with end-of-life care.

Publications by the Alzheimer's Society were also highlighting the need for care from diagnosis until the end-of-life for people living with dementia (Kings College London, London School of Economics & Alzheimer's Society, 2007). In a subsequent report focusing on improvements of care in care homes or on hospital wards any mention of death is incidental (Alzheimer's Society, 2007, Alzheimer's Society, 2009), there is no mention of palliative or hospice care. A 2009 report did comment on the need for commissioners to consider a palliative care approach for people living with advanced dementia (Alzheimer's Society, 2009). Marie Curie, also produced a report in 2009 following a specific project in London in which the National Council for Palliative Care were a partner. This report accepted that palliative care was a stakeholder in planning services for people with dementia, but the report also highlighted that hospice 'staff rarely had contact with people with dementia and showed concern about their limited ability to manage the behavioural and psychiatric symptoms.' (Marie Curie, 2009, p. 17). These reports contribute to a perception of concern about describing dementia as a palliative disease during a time focused on diagnosis and cure and uncertainty of the role of hospices.

At this point the literature is building in relation to government policy supporting improvements in care for people with dementia but with a clear focus on awareness and diagnosis. National dementia charities whilst recognising the need for good end-of-life care, are fairly quiet but growing in their voice in relation to palliative care and silent on hospice.

The National Council for Palliative Care seems to be a lone voice, having a debate largely with itself in multiple reports challenging specialist palliative care providers and hospices to shift from their institutional norms. There are a few hospices starting to explore services relating to care for people with dementia. In 2011, hospices are over forty years old at this point and there hasn't been significant shift in non-malignant care (NCPC, 2011). Hospice UK are not seemingly proactive at this point in challenging their members practice on the issue of dementia.

Organisations such as NCPC may well be legitimating organisations. However, the lack of clarity regarding models of care, and the confusion regarding the need for either palliative or specialist palliative care reduced the potential impact on other organisations in the field. The lack of clarity as to whether hospices should be developing an interest in the growing prevalence of people with dementia undermines the potential for acts of disruptive institutional work. There may well be evidence of attempts to undermine associations and beliefs, but there doesn't appear to be any acts of institutional entrepreneurship creating a unified call for social action.

3.4.2 Part two - 2012 onwards

Dementia policy took centre stage following David Cameron's 2012 dementia challenge pledge. In March 2012 David Cameron suggested that the country had been in denial regarding the impact and scale of dementia. He suggested the need for an 'all out fight-back' and described dementia as a 'national crisis' and likened the type of campaign needed to cancer in the 70s and HIV in the 80s and 90s. His 'personal priority' was for 'Britain to be a world leader in dementia research and care' (Cameron, 2012). The choice of language in this speech is a very clear call for action and adds to the discourse creating impetus for change.

David Cameron did not mention end-of-life care, palliative or 'dying' in his speech. In fact, the 2012 publication following his speech 'Prime Ministers

Challenge on Dementia' only referenced dying in one aim stating 'I am confident that my end-of-life wishes will be respected. I can expect a good death' (DOH, 2012, p. 26).

The impact of David Cameron's challenge could be described as a field configuring event (Hardy & Maguire, 2010) as described in page 95. The reports and speeches created a new impetus for discourse and created opportunity for actors within the field of dementia for example the Alzheimer's Society's, Dementia Friends programme was launched as part of this national focus. However, hospices were on the fringes of this activity and therefore the field-configuration happening in the field of dementia, did not significantly influence change within the field of hospice care.

David Cameron's Prime Minister's Challenge was launched alongside a report by the Alzheimer's Society which identifies a wide range of challenges including that of good care at end-of-life, the outcome developed into 'I will die free from pain and fear, and with dignity, cared for by people who are trained and supported in high quality palliative care' (Alzheimer's Society, 2012 i). This is interesting as it is a very specific link between end-of-life care and palliative care for people with dementia.

Later in 2012, the Alzheimer's Society published another report, *My Life until the End: Dying Well with Dementia*, specifically relating to the challenges of good end-of-life care. This report acknowledges a variety of challenges relating to improved end-of-life care, including issues relating to symptom control such as pain and holistic care (Alzheimer's Society, 2012 ii).

The report makes specific reference to hospice stating that: -

- 'More should be done to extend dementia training in the hospice environment, recognising dementia as a specialist care need' and
- 'Hospices and specialist palliative care services should review their policies and practices to enable joint working to meet the needs of people with dementia in their communities.' (Alzheimer's Society, 2012 i, p. vii).

This is interesting due to the reference to specialist palliative care and dementia requiring specialist care. As discussed in Chapter One, definitions and the issue of specialist versus generalist is a key issue relating to the development of hospices as institutions and the norms, beliefs and values of professionals on the issue of 'specialist care'. The report recognises that hospice care professionals may struggle to care for people with dementia who have a different disease trajectory in comparison to people with cancer. However, the report also acknowledges that emotional support at end-of-life and bereavement care are not routinely available outside of hospice care and that this would be valuable for people with dementia and their families. This report references previous work by NCPC however, does not reference or appear to have liaised with Hospice UK.

The call for improvements in end-of-life care grows in the literature and the Prime Minister's follow up report, 'Prime Minister's challenge on dementia 2020' (Department of Health and Social Care, 2015) does make specific reference to palliative and end-of-life care, specifically around early conversations relating to issues such as preferred place of care at end-of-life, improved coordination of care and advance care planning.

End-of-life Care and Palliative Care were also referred to in the Dementia State of the Nation Report in 2013 quoting Cicely Saunders and focusing on the need for earlier conversations regarding plans for end-of-life care for people with dementia (DOH, 2013).

In 2013 Hospice UK published the report of the Commission into the Future of Hospice Care (Help the Hospices, 2013) which outlined many of the challenges facing hospices in particular around issues of increased access and the increasing number and complexity of older people needing care. The report suggested that 'the test for hospices will be whether they can develop the greater reach, accessibility and complexity of service required to meet the anticipated needs of many different groups of people who would benefit from hospice care' and that 'the Commission heard a passionate and convincing call for the engagement of hospices in end-of-life care for people with this condition [dementia] given its high symptom and disability burdens and the challenges faced by carers' (Help the Hospices, 2013, p. 17).

Marie Curie and the Alzheimer's Society collaborated on a report 'Living and Dying with Dementia in England: Barriers to Care (2014) – which highlighted that 'less than 1% of people in hospice in Europe had a primary diagnosis of dementia' (Marie Curie, Alzheimer's Society, 2014, p. 9). The report suggested that the lack of referral was due to the fact that dementia was not being recognised as a terminal condition and that in doing so access to services would increase. The report recognises that there are hospices starting to provide services for people with dementia and recognises some of the institutional history and challenges faced i.e. norms for staff set only in relation to care for people with cancer (Marie Curie, Alzheimer's Society, 2014). It appears that policy is recognising the connections however, the organisational field of hospice is not, possibly because dementia just is not part of the narrative and historical development of the movement.

Hospice UK published 'Hospice Enabled Dementia Care – the first steps' (Hospice UK, 2015). This was launched at a conference with speakers discussing some of the issues and opportunities around hospice care for people with dementia. This event was a field-configuring event within the field of hospice

care and created opportunity for discourse potentially leading to change. The publication proposed ways by which hospices could start to engage with this agenda focusing in particular on new partnerships recognising that hospices may have a part to play rather than perhaps being primary care provider. This approach might alleviate the concerns by hospices as to how they manage this group of patients. Hospice UK as a meta-organisation has to both support the views of its members in addition to attempting to influence a change in the field where they think it is advisable given the national picture.

The report adds to the literature relating to the relevance of palliative care and hospice care for people with dementia and the needs for improvement in care in addition to recognising the challenges for hospices in meeting the needs of a new group of patients.

The report cites Linda McEnhill who is a hospice service manager and a member of Hospice UK's Dementia Project Steering Group. She suggests that the discourse relating to hospices involvement in dementia misses the key point of human rights and that it is 'unlawful' and 'ethically dubious' for a service that has some public funding to 'refuse to adapt its services for all those who need them' (Hospice UK, 2015, p. 10). McEnhill purports that families could complain under the Equality Act 2010 if hospices did not provide a service and that the language of choice is at odds with the legal position. This is a difficult argument when there are many organisations specialising in particular conditions, one could argue that someone with cancer would also be entitled access a service specifically provided for people with MS, Parkinson's disease, MND or Dementia. Equally hospices are not fully funded by the state and therefore where there are funding challenges, decisions about what is affordable and sustainable is a tension to any human rights argument.

The Hospice UK (2015) report outlines results of a survey of hospices, although unfortunately a low response rates of only 25 from across the movement. The

data is consistent with the findings of Amador et al. (2016) and NCPC (2008, 2009) who also found that barriers to engagement in dementia care services are listed as: -

- 'Limited applicability of the existing model of care to respond to the specific needs of people with dementia.
- People with dementia are not seen as people who would typically benefit from hospice care
- Weak working relationships with external professionals such as mental health specialists
- The unsuitability of the hospice physical environment
- Concern about growing levels of need and demand for hospice services' (Hospice UK, 2015, p. 14).

The low response to the survey means that similarly to Amador et al.'s (2016) study the results cannot be generalised. However, in describing the barriers, the summary has a feeling of reluctance from some hospice teams to accept people with dementia into their services. The Hospice Enabled Dementia Care (Hospice UK, 2015) report cited case studies of several examples of hospices involved in supporting people with dementia and highlights many of the strengths that hospices can offer, in partnership with others, to this agenda. The report concluded with key objectives and a checklist for hospices in taking forward the model of 'hospice enabled dementia care'.

However, it also demonstrated that Hospice UK is starting to question the legitimacy of hospice providers who do not support people with dementia. As a legitimating organisation, Hospice UK has power to influence direction via acts of institutional work such as providing grant funding for specific projects around dementia.

There is (according to Hospice UK) an imperative that hospices work in partnership to develop Hospice Enabled Dementia Care, that there is a

'passionate and convincing call' from the public (Help the Hospices, 2013) and the suggestion of a legal requirement (Hospice UK, 2015). It should of course be recognised that Hospice UK, like other special interest groups, are not neutral in their reporting.

This section has focused on policy literature relating to hospice and dementia care. It demonstrates the growing awareness by both government and relevant national organisations that end-of-life care for people with dementia is becoming a priority and a challenge. It adds weight to the growing sense of expectation that hospices will be part of a solution. Section 3.5 reviews available empirical literature to consider what knowledge already exists in relation to hospices as organisations and the challenge of dementia.

3.5 Empirical literature in relation to hospice organisational literature

Organisational

There is a gap in the literature relating to hospice care for people with dementia in the UK from the perspective of the organisation and/or field. There is also a gap in research relating to hospices as organisations regardless of the topic of dementia. This gap was confirmed via the literature search.

There are only a small number of UK papers that discuss hospice in the context of organisational theory including: James and Field (1992); Johnson (1999), Clark (1998) and Croft (2010).

James and Field (1992) utilise Weber's theory of charismatic leadership and bureaucratization as means of describing the development of the hospice movement during the twenty-five years since the opening of St Christopher's Hospice. The abstract offered much stating that a 'process of diversification and legitimation' has resulted in 'mainstream influence' and that the way that the hospice movement was developed has resulted in 'pressures toward

bureaucratization and professionalisation' 'leading to the routinization of hospice care'. The abstract concluded that it will 'consider whether it is possible for the hospice movement to sustain its founding ideals' (James & Field, 1992, p. 1363). This is an ambitious set of expectations to cover in one article and the article therefore is quite broad in its analysis and conclusion.

Charisma and routinization is a legitimate theory in which to explore elements of the history of hospice, however, other theories also have a perspective to offer that might be more useful. James and Field (1992) quote Andreski (1984, p. 108) who in studying Weber's work described a charismatic leader as one 'who has no organised machine at its disposal and whose power has not been gained through institutional procedure'. James and Field (1992) describe Weber's view of charismatic leadership as one that 'focuses attention on the possibility for exceptional individuals to act as a catalyst for social change (James & Field, 1992, p. 1365).

James and Field (1992) are proposing a view of charisma taking priority over planning. Recognising the fact that the James and Field (1992) article is 26 years old and that the story of Cicely Saunders has been told many times since then, the article highlights some of the now well-known facts about founding decisions, such as the establishment of St Christopher's outside of the national health service. They also propose however, as part of their argument, that there was a lack of organisational planning behind the idea of hospice (Boulay, 2007, James and Field, 1992). David Clark's article 'Originating a movement: Cicely Saunders and the development of St Christopher's Hospice, 1957-1967' offers insight into the very careful planning and networking prior to the hospice opening its doors (Clark, 1998). In fact, he explicitly contests the perspective provided in James and Field's, 1992 article citing 'routinization and bureaucracy' as problems and argues they missed the fact that according to Clark (1998) these issues were indeed anticipated.

Cicely Saunders built the formal structure of an organisation alongside her charismatic leadership and vision. Many of the individuals that became part of the hospice story were from professional institutional backgrounds, as was Cicely herself and perhaps therefore had the ability to create an entity accepted as legitimate alongside statutory provision. This is where alternative organisational theories such as Institutional Work Theory, Institutional Entrepreneurship or Social Movement Theory may have been useful. For example, bricolage, from Social Movement theory, describes the 'blending and reblending of elements of several important social institutions' (Campbell, 2005 p.57) providing a way of exploring how Cicely Saunders drew on symbolic and technical elements from nursing, social work, medicine and religion. These elements were brought together to create the ethos of hospice care from institutions in which Cicely Saunders, and others belonged. Institutions already have norms, values, processes and behaviours that would need to integrate as part of the organisation of hospice. In addition founders recruited people to their Boards who had the skills to underpin the idea of hospice with structure and funding (Brothwell, 2016). The point of this review of James and Field's (1992) paper and David Clark's retort (1998) is that a wider perspective of organisational theory such as institutionalism and its historical roots help deepen the understanding of the evolution of the hospice movement.

Without disputing the centrality of St Christopher's in the founding of the movement, the mechanism by which it was established is not unique, other hospices also formed committees and structures to gain the support and resources that were required (Johnson, 1999, Brothwell, 2016).

Johnson (1999) compared the governance and leadership of 77 independent hospices, his analysis found that on average founding groups were made up of 12 people. He concludes that it is issues relating to maintaining the corporate vision that support sustainability rather than the ongoing involvement of

charismatic leaders. Johnson (1991) advocates the use of institutional analysis, however, doesn't really provide any background as to what this is. He states that 'the sense the hospice is the property of the supporting community is usually well embedded', whilst this is consistent with old institutional theory he does not provide any context for this statement. He provides two examples and argues that they 'illustrate the value of an institutional analysis approach which seeks to establish all outside centre of influence involved in these types of organisations' (Johnson, 1999, p. 28).

Johnson's (1999) article is helpful in describing some of the early governance of the emerging hospice movement. However, the article is not positioned within a theoretical field and therefore, it does not adequately argue the merits of institutional analysis. Croft (2010), recognised elements of institutional theory in his grounded theory study of hospice governance. He discusses issues of isomorphism i.e. how organisations providing similar services tend to demonstrate similarity. This similarity is one of the elements that creates an organisational field and therefore is relevant to hospices. Croft (2010) adds some useful insight into some of the internal challenges within a hospice such as challenges of balancing altruism and governance.

Clark (1998) and Johnson (1999) demonstrated that hospices were formulating recognised structures for governance and management in their planning phases. Whilst being established outside of the NHS many of the staff working within hospices were healthcare professionals, i.e. nurses and doctors. If it is accepted that professions by their very nature are institutionalised (Muzio, et al., 2013), there should be no surprise that many of the practices were routinized. Cicely Saunders, through the process of bricolage and through her personal development and professional journey, brought in practices from long standing institutions such as nursing, social work, medicine and religion that she believed

were the best for her patients at end-of-life, creating the concept of total pain (Boulay, 2007, Clark, 2016 i).

The fact that hospices become routinized and bureaucratic (James & Field, 1992) is just a matter of the natural lifecycle of social movements (Giddens and Sutton, 2013) and in fact many innovations. This should not be a surprise or a criticism, however, understanding the complex nature of institutions and the theories that help explain them does provide insight into why hospices are the way they are today.

The lack of literature relating to hospices as organisations or institutions did not however, mean that institutional or organisational factors have not been explored in other articles. Therefore, the literature search was extended to include empirical data of research relating to organisational elements of hospice i.e. micro level organisational studies within an organisation to explore if there was additional data that adds to the understanding of hospices in relation to institutional factors and change. These articles have been chosen because they specifically deal with areas of change and loosely fall into three categories i) non-clinical ii) articles relating to services for people with dementia and iii) articles relating to care for non-malignant disease.

Included in this search were articles relating to non-clinical service developments or studies in hospices. There were two articles that explicitly fitted into this category. Snowden and Kolb (2016) published an article following a mixed methods research study into the unintended consequences of implementing an electronic patient record. Their research demonstrated that despite the technical challenges, one of the key themes from the data related to nursing identity and that the use of an electronic record removed something of value in the role between the nurse and the patient. There are elements in this research that are consistent with institutional organisational theory and issues of norms, stories and values. One of the conclusions was that over and above learning how to use

the software that 'more significantly they are having to find new ways to reconstruct the narratives they have been using all their careers to communicate the patient story' (Snowden & Kolb, 2016, p. 1423). The article referenced narrative theory and recognises the impact of organisational culture their study, however, does not refer to institutional organisational theory.

The other article, by Jones & Sambrook, (2010) is of particular interest in adding a new perspective in comparison to the other literature resulting from the search. This grounded theory research including in depth interviews focused on the nature of psychological contracts of UK hospice nurses, although the study only focused on four hospices near to each other. The article describes the psychological contract as a cognitive agreement between the employer and employee in relation their respective expectations. The research found that the ten nurses who participated formed their psychological contract with their patients, then their colleagues and not their organisations. This doesn't appear to be because of a common theme of being unhappy with their employer although there was some evidence of low morale. The research doesn't report whether, after their patients and colleagues, their psychological contract is then with their employer or their profession and whether their profession is 'palliative care nurses' and then 'nurse'. What this adds to the consideration of institutional theory within hospices is that if the psychological contract is not with the employer i.e. the norms, values, expectations associated with the institution at an organisational level and not with the 'profession' (palliative care nursing) then even if change is perceived as legitimate by both the institution and the profession, the hospice nurse will potentially perceive a breach of their contract with the patients. It is an interesting angle that is worthy of further research i.e. the extent to which a hospice nurse's psychological contract is with patients with cancer; patients needing specialist palliative care or all patients? Whilst this article does not refer to institutional theory, there appears to be a connection

between the psychological contract and employee behaviour and therefore has something to add to the discourse.

Dementia

There were two articles that came up in the search that were relevant to the institutional factors or organisational change within hospices rather than the applicability of care for people with dementia discussed earlier in this chapter.

Lee, et al., 2017 conducted semi-structured interviews and focus groups including a range of stakeholders including hospice staff. In looking specifically for issues relating to hospice or specialist palliative care teams, there are comments relating to the perceived inexperience of hospice staff in caring for people with dementia. The article reports that hospice staff believed their role would be one of outreach and education with the suggestion that this was due to deficiencies within the care home sector, although they felt that they coped very well in delivering end-of-life care for people with dementia. The most valuable contribution of the Lee et al. (2017) article in the context of this thesis is the suggestion that there is both little interest and a 'fear' experienced by hospice staff relating to caring for people with dementia. In addition, the article proposes that there was little acknowledgment by specialist palliative care teams that there may be expertise in other services that 'could be of value' (Lee, et al., 2017, p. 13). The article adds little to the evidence base around institutional factors. However, the second article by Davies et al. (2014) focused on barriers to provision of palliative care for people with dementia, which also used semi-structured interviews does have an institutional contribution. The article discusses the 'systemisation' i.e. 'the growing number of guidelines, standards, rules and regulations' in palliative care. One palliative care nurse participant in the interviews described 'breaking the rules, breaking the boundaries, working at the edge all of the time' in the early years of palliative care and their frustration in having to work within 'parameters' due to a 'shift in clinical governance' and a

second commenting about their desire to continue to 'think outside the box' (Davies, et al., 2014, p. 389). There is a recognition by participants that in negotiating who should be providing what care to whom that there are 'threats to a specialism, threats to generalism, you know um professional rivalries and jealousies' (Davies, et al., 2014, p. 391). These comments reflect issues of institutionalism i.e. norms, the perceived 'values of how things use to be' and professional identity. However, again it does not position the research within institutional theory and therefore does not explore these issues.

Non-malignant disease

There were seven articles that formed this category (see Appendix One, page 244). McCaughan, et al., 2018 study 'Palliative care specialists' perceptions concerning referral of haematology patient to their services : findings from a qualitative study' actually relates to malignant disease. However, it is relevant within this sub section as the article suggests that patients with cancer cared for under haematology are not as often referred to specialist palliative care (McCaughan, et al., 2018), therefore this also potentially becomes an 'excluded' category of patients. The study conducted twenty semi-structured interviews with doctors and nurses from hospital, hospice and community settings. There are similar issues raised in this article to that related to dementia e.g. lack of certainty of the trajectory of the disease, perspectives that hospice or specialist palliative care is only relevant at the end stage of disease, a perception that referring means 'giving up' on the patient and a lack of knowledge of different roles. This study does not attempt to be from an organisational lens, however, it raises similar issues to the focus of this thesis.

Two studies came up in the literature search published in 2007 relating to the lack of hospice and palliative care for people with heart failure or chronic heart disease, (Pooler, et al., 2007, Selman, et al., 2007). Ironically this was ten years prior to Hospice UK's publication 'Heart Failure and Hospice care: how to

make a difference, published in 2017 trying to support hospices seeking to better meet the needs of this population (Hospice UK, 2017 i). This ten-year gap, arguably demonstrated the lack of progress in changing the narrative of hospice care. Pooler et al.'s (2007) discussion piece, focused on care at home and highlighted the need for heart failure nurses, and in this case Macmillan nurses, to understand both each other's role and agree boundaries of care. In addition, it was acknowledged the Macmillan nurses would have to learn about a different disease and group of patients and that cardiologists would have to accept their patient was going to die. Selman et al. (2007) conducted their research via semi-structured telephone interviews focusing on palliative care services for people with chronic heart disease. The method recognised that their data may have missed some palliative care services that were starting to develop services for people with chronic heart disease. Their article lists some very practical issues including four that sound institutional in nature i.e. 'territorial impulses and protectionism', 'denial of death' [by cardiologists], 'dominance of medical model', 'resistance to palliative care due to misperceptions and stigma' [by patients]. Other factors are very similar to previous articles in relation to understanding of roles, joint working, funding and workforce development.

A further study (Wosahlo, 2014) relating to change in hospices was to do with the acceptance of a rehabilitative approach to palliative care which in particular applies to patients with a longer trajectory and non-malignant disease. The study used the Stakeholder Salience Model to assess issues relating to power, legitimacy, stakeholder relationships and urgency for change. The study also identified the culture surrounding professional identity and legitimacy of less dominant healthcare groups such as Allied Health Professionals. Their study concluded that leadership roles and power were most important in bringing forward a rehabilitative approach to palliative care in hospices (Wosahlo, 2014). Some of the issues in this study may be similar to those relating to dementia, i.e.

the extent to which different groups of healthcare professionals see caring for people with dementia as a legitimate role for 'specialists in palliative care'.

The final three papers in this section are commentaries on the general provision of hospice or palliative care for people with non-malignant disease. Field and Addington-Hall (1999) provide an evidence-based discussion on needs and barriers for people who could benefit from specialist palliative care. The arguments relating to the dominance of care and the call for equity of access are in many ways similar to those discussed today. The article highlights five barriers:-

- 'The potential lack of skills amongst specialist palliative care experts in the field of non-cancer pain
- The difficulties of identifying candidates for specialist palliative care services
- The lack of information on the acceptability of these services to non-cancer patients
- The resource implications of extending specialist palliative care services
- Vested interests in present arrangements' (Field & Addington-Hall, 1999, p. 1275).

The first four of these are practical organisational factors and are consistent with the other articles relating to extending palliative care beyond cancer, therefore there is no need to revisit detail behind those in this thesis. However, the 'vested interests', might suggest something institutional, the article doesn't discuss each of these bullets in turn making it difficult to be clear how the vested interests were evident as a barrier. Within a section regarding 'relationships with other healthcare providers' (Field and Addington-Hall, 1999 p.1277) there is reference to perceived consequences to providers i.e. whether new services are replacements impacting on existing teams, the potential of de-skilling other professionals, competition between providers for resources and integration

impacting existing models of delivery. The article proposes in its conclusion that 'institutional and personal rewards follow on from exercising power and influence at local and national levels'. It suggests that the 'interests of hospices and other palliative care organisations and professionals become linked to continuing expansion' and that this leads to increasing 'professionalisation'. However, despite recognising for some interested parties such as patients, families and employees this might be positive it warns that this growth might lead to 'goal displacement'. This section of the article is confusing, the main body has discussed all of the barriers and difficulties of expanding specialist palliative care, however, then appears to conclude that hospices want to grow and diversify. The article does not explore the issues of institutional change which would provide a vested interest argument that hospices not wanting to change, not wanting to move radically beyond cancer i.e. broadly maintaining the organisation, which, with hindsight, nearly twenty years later appears to be what has happened.

Willis et al. (2014) suggests a 'moral compulsion is driving the hospice movement to increase care targeted at those in the 'non-cancer' category to better satisfy numerical proportionality' (Willis, et al., 2014, p. 121). The article in discussing the issue of 'autonomy' comments on elements of the debate relating to human rights and dementia (Hospice UK, 2015) putting forwards a view that should someone have the right to choose that a service be available and does this mean organisations are duty bound to provide it or the workforce equally obliged to train to deliver it. The article does touch on the issue of legitimacy in discussing autonomy and organisational decision making, recognising an independent organisation can decide what it feels is legitimate for it to provide or not provide. Willis et al. (2014) argue that 'fairness and justice' should be about who gets access to a particular symptom management regime rather than access being by disease and that different regions may have different profiles of disease. This might mean that patient proportionality does not radically change if the patients

most needing specialist palliative care are indeed getting it. This is an interesting commentary. It recognises a 'moral compulsion' to move beyond cancer due to both patient need and the criticism levelled at the sector for advantaging a particular patient group. It also recognises legitimacy and choice both by patients, the workforce and organisations by discussing autonomy from different stakeholder angles. The article is crying out for a recognition of institutional theory and the perspective this would give – the values, norms and narrative of the charity, the roles of people exercising institutional work such as those disrupting based on 'moral compulsion' and 'autonomy' and those attempting to maintain the status quo based on their perception of legitimacy.

The final paper in this section is a short commentary by Robert Becker (2017) who adds a gloomy view on 'meeting the palliative care needs of people with non-cancer conditions'. Becker (2017) outlines the challenges recognising that hospice care, through charitable donations, has added millions into the health economy for spending on predominately cancer care. He also balances this with the inequity therefore of provision for other conditions including dementia. However, he is critical in that while the policy documents have consistently argued for a change (Alzheimer's Society, 2016, Alzheimer's Society and Marie Curie Cancer Care, 2014, DOH, 2008 and NCPC, 2006) there has been no significant shift. He contests that the 'political will is simply not there and never will be' and that it would 'mean a paradigm shift in our cultural thinking and health priorities' (Becker, 2017, p. 472). He believes that the government nor the public would fund it due to the diversion of funds that are currently focused on cancer.

Becker (2017) talked about the needs to de-institutionalise and re-institutionalise demonstrating through the stages of the model by Greenwood, et al., (2002). He does not use that language, his commentary is not setting out a theoretical position. However, what he outlined is one critical part of the debate into the

future of the hospice movement. Would the public accept it as legitimate for hospices to care for people from a wider disease group IF it meant seeing less people with cancer. This is a fundamental question that needs to be addressed to provide confidence for hospice leaders in changing the focus of their care provision.

In this section the areas of literature searched relate to hospices as institutions or organisations. It is apparent there is very little research. The three articles in this initial phase add a view and counter view on the issue of 'routinization' and the extent to which this was anticipated and planned for. The Johnson (1999) article does provide some empirical data relating to hospice trustees and governance structure which provides a perspective on early planning however, adds very little to this thesis.

The eleven articles in this extended search provide useful empirical data and commentary that adds to the discourse within this thesis. However, none of the articles significantly contribute to addressing the question of how organisational factors might be influencing the development of hospice services for people with dementia.

There are some common themes between articles in relation to dementia and other non-malignant disease and in fact relating to malignant disease in relation to disease trajectory, understanding of different roles, the need for workforce development and the need for greater collaboration between stakeholders.

There are some glimmers of institutional thinking implicit within some of the articles that contribute to the analysis in this thesis. Snowden and Kolb (2016) describe the need to revisit narratives, Jones and Sambrook (2010) add an interesting angle on which to reflect, relating to the psychological contract.

Davies, et al., (2013) touch on issues relating to 'systemisation' and participants in their research reflecting on their perceived values of the past in relation to palliative care. Selman, et al., (2007) also reflect some comment by participants

that sound institutional in nature relating to their views of others services, 'territorial impulses' (Selman, et al., 2007, p. 387) and medicalised models. Willis, et al., (2014) and Becker (2017) further add some institutional factors with Willis et al. (2014) focusing on issues of 'moral compulsion' and autonomy that add to view on disrupting or maintaining institutions whilst Becker (2017) described a paradigm shift that could be described via the stages of institutional change outlined in Greenwood et al.'s (2002) model.

Despite these glimmers and near collision of institutional thinking and hospice care, there is such a significant gap in the literature it would be fair to assume this theoretical framework has not been applied to hospices. In framing an inquiry around institutional theory it is hoped that new insights can be derived around identity, legitimacy and institutional change. Greenwood et al.'s (2002) model (Figure 2.1) can provide an analytical framework to frame part of this discussion.

Chapter summary

This chapter has outlined the literature search completed and the types of literature used to provide the reader with a broad understanding of the background, policy and existing knowledge relevant to the research topic.

The chapter demonstrates that hospice care for people with dementia is applicable clinically and that there are deficits in palliative care for this group of people which could possibly be reduced by involvement of the hospice sector. In addition, there is a clear policy direction for general improvements in end-of-life care for people without cancer and a specific call for improvements for people with dementia. There is also policy literature that creates a challenge to the hospice sector in determining a strategic and clinical response. Finally, the discussion on existing research demonstrates a gap in knowledge relating to hospices as institutions or organisations, however, does indicate how this theoretical framework may support hospices in implementing change.

Reflection

I have enjoyed writing this chapter and the greatest challenge was not writing too much. I confess to getting rather side-tracked and spent quite some time finding out more about how hospices other than St Christopher's and St Giles formed. Having written way more than necessary, I had to refocus and consider what was relevant. The timing of the publication of David Clark's book 'To Comfort Always: A history of palliative medicine since the nineteenth century' (Clark, 2016 i) was fortuitous. I had the pleasure of hearing him speak at the Hospice UK Conference (Clark, 2016 ii) and also watching Jenny van der Steen present her work on the applicability of palliative care for people with dementia. It was more difficult writing the empirical section of this chapter since there is so very little written on hospices as organisations, however, expanding the search terms did help find some relevant articles relating to conditions other than dementia that also provided some challenge to hospice care.

4 Chapter Four – methods and process

The aim of this chapter is to provide details of the research methods to address the research topic **‘A mixed methods study exploring organisational factors influencing the development of services for people with dementia in English hospices’**

The methodology will be explored from both a philosophical perspective, (i.e. epistemology, ontology and theory) and from a practical perspective (research design and methods of collecting and analysing data). The chapter will start by demonstrating the methods selected in relation to the research questions.

4.1 Research questions and objectives

As discussed in Chapter Three, the research title was refined following the ECLIPSE search strategy.

The research topic needs dissecting, Table 4.1 provides an overview of the sub-questions being considered within this research, the objectives for each of these questions and the methods by which these questions will be addressed.

Table 4.1 - research questions in relation to methods

Key question one - To what extent does the history, culture and identity of the hospice movement support or inhibit responses by hospices to the pressure (in policy, demographic changes and public expectation) of developing services for people with dementia?		
Sub-elements	Objectives of the question	Method
i. How are hospices defined?	To provide a description of the focus for the research and to build a narrative around the research topic	Literature review, interviews and focus group
ii. How is the 'field' of hospice care (hospices collectively) defined and organised?	To build a descriptive narrative around the 'field' of hospice care, i.e. the hospice movement	Literature review, interviews and focus group
iii. How are hospices, individually and as a 'field' responding to or reflecting on the pressures to develop services	To understand different views and perspectives on the issue of hospice services for people with dementia	Literature review, survey, interviews and focus group

for people with dementia		
iv. What is the role of Hospice UK (the movement's membership organisation) in influencing hospices on the topic of dementia?	To consider the potential influence of a membership organisation and to understand their national position on services for people with dementia	Literature review, interviews
v. How have hospices engaged with the dilemma of services for people with dementia and what are the associated barriers?	To understand the response to the issue of services for people with dementia	Literature review, survey, focus group and interviews
<p>Key question two - Given this exploration of these organisational factors, what are the prospects for a (collective) response by hospices to the challenges posed by the demographic changes being faced?</p>		

	To understand the challenge at 'field level' and consider how a response might be posed	Literature review, survey, focus group and interviews
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The chapter will now follow a framework by Creswell and Plano Clark (2007) which describes four levels of developing a research study adapted from work by Crotty (1998):

1. Paradigm worldview
2. Theoretical Lens
3. Methodological Approach and
4. Methods of data collection (Creswell and Plano Clark 2007, p39).

4.2 Paradigm worldview

At a simplistic level, research is described as quantitative, qualitative or mixed methods (Creswell & Plano Clark, 2011). This research is mixed methods in nature, with a qualitative bias. However, as Ritchie et al. (2014) outline there are many approaches taken by qualitative researchers relating to ontology i.e. 'what is the nature of the social world and what is there to know about it' and epistemology i.e. 'how can we learn about the social world and what is the basis of our knowledge' (Ritchie, et al., 2014, p. 4). These approaches relate to how the researcher gains knowledge or perceives truth and how truth is constructed (Grbich, 2007; Creswell and Plano Clark, 2007).

Ontology asks questions around social reality such as 'is there a social reality that exists independently of human conceptions and interpretations' and 'whether there is a shared social reality of only multiple, context-specific ones' (Ritchie, et al., 2014, p. 4). Ontologically there are two different positions that of realism and idealism. Realists believe that 'an external reality exists independent of our beliefs or understanding' and idealists believe the opposite that reality is created

through 'socially constructed meanings' (Ritchie, et al., 2014, p. 5). The ontological perspective of this thesis is that of an idealist.

Epistemology relates to how one seeks knowledge or how to understand it (Ritchie, et al., 2014) and comprises of two main concepts i) inductive or deductive i.e. how knowledge is gained and ii) interpretivist or positivist. Simplistically, an inductive approach gains evidence to generate a conclusion whereas a deductive method will start with a hypothesis or conclusion and then seek evidence to test it. However, research might not necessarily be purely inductive or deductive and the researcher may influence in some way how a hypothesis is constructed or how data is interpreted (Blaikie, 2007 cited by Ritchie, et al., 2014). This must be particularly true for insider researchers i.e. not being able to completely disregard their own experiences or any views they hold. Due to the researcher's involvement in discussions and presentations of issues relating to hospice services for people with dementia, it would be wrong to not acknowledge that some participants may perceive a bias. This research aims to follow an inductive approach and therefore, must ensure that the methods and analysis are rigorous to ensure that the researcher's insider perspectives are not creating a question of validity with the study.

The other element of epistemology is that of positivist or interpretivist. A positivist is seeking objectivity and an absolute truth (Grbich, 2009) whereas an interpretivist accepts subjectivity as part of knowledge and therefore accepts in creating meaning that unseen matters such as; culture, interactions or feelings are important not just what might be perceived as scientific facts (Hatch and Cunliffe 2013). However, there is a middle ground, pragmatism, which is where this research is positioned. There are different views as to whether pragmatism is a separate research paradigm, described as a 'third methodological movement' (Johnson and Onwuegbuzie, 2004, p.15 cited by Creswell and Plano Clark, 2007) or simply a flexible approach considering multiple world views (Creswell

and Plano Clark 2007). Mixed methods research is at a basic level, aligned with this second view of pragmatism; this research is also influenced by pragmatism as a research paradigm in its own right.

'Pragmatism connects 'body and mind' there is no separation in how knowledge is understood "that truth arises out of interaction, is enacted rather than discovered' (Strauss, 1993). Strauss identifies three key components of pragmatism;

- i. 'Theorizing action
- ii. Studying social processes
- iii. Placing events at the base of analysis' (Strauss, 1993, p. xiii)

There is a natural alignment between this thesis, the researcher and Mead's development of pragmatism and his view of 'truth'. He describes the environment, as something always changing and evolving and how therefore truth is also always evolving and never fixed. Mead and other pragmatists such as Dewey, James, Pierce (Thayer, 1982) aimed to demonstrate how scientific methods could be applied to subjects such as sociology and psychology (Baldwin, 1986). Mead suggested that the scientific method is based on 'the continuous investigation of and readjustment to an ever changing and evolving environment' (Baldwin, 1986 p16). This, Mead concluded, meant that there could only be a 'provisional truth' (Baldwin, 1986 p19), i.e. if the environment is ever evolving, what might be 'truth' today may not be 'truth' at a future point in time. One of the contested elements of pragmatism is the level of critical thinking. Crotty (1998) describes the early American Pragmatists as 'constructionist and critical' and suggests over time the critical nature was lost and that symbolic interpretation and pragmatism assumed a peaceful world of interactions whereas critical theorists see a world of power and corruption which would influence such interactions. However, Mead may not have meant his work to be interpreted in

this way as he was involved in issues of social justice which are difficult to consider with a purely peaceful view of society (Baldwin 1986).

In the context of institutional theory, institution is a 'more or less taken for granted repetitive social behaviour that is underpinned by normative systems and cognitive understandings that give meaning to social exchange and thus enable self-reproducing social order' (Greenwood, et al., 2008, pp. 4-5). This is consistent with Mead who describes socialisation in a way which could be easily also be attributed to institutionalisation e.g. how 'individuals acquire symbols, thoughts and behaviours from their society' (Baldwin, 1986, p. 123). Mead's work was recognised more for his contribution to micro analysis of self, however, within his work on a unified system he did not exclude the macro connection of society or institution (Baldwin, 1986).

Mead argues that individuals have a 'common response in varied forms' and that these various responses from different perspectives 'have an organisation which gives unity'. Therefore 'the institution represents a common response on the part of all members of the community to a particular situation' (Mead, 2015, p. 261). Mead therefore is recognising individuality of a response to a common purpose and supports the need for institutions that are 'flexible and progressive, fostering individuality rather than discouraging it' (Mead, 2015, p. 262). This is relevant in the context of hospice, people choose their relationship and understanding of the institution they support whether that be through being employed, volunteering or in raising funds.

Social Constructionism and Symbolic Interactionism are theories that have grown out of the philosophy of pragmatism. Social Constructivists suggest that truth or meaning is gathered from individuals' views, interactions with others, cultural and historical influences (Grbich, 2007; Cresswell and Plano Clark, 2011). Social constructivists believe that research participants are 'speaking from meanings shaped by social interaction with others and from their own personal histories'

(Creswell & Plano Clark, 2011). Symbolic interactionism focuses on the interactions between people with three main principles

- 'Human beings act toward things on the basis of the meanings that the things have for them
- That the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows
- That these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters' (Blumer, 1969, p. 2)

Berger and Luckmann linked their early work with later institutional thinking. They argued that 'the sociology of knowledge must concern itself with everything that passes for 'knowledge' in society' (Berger and Luckman cited by Scott 2008, p16) articulating that social reality is based on the interactions, meanings and symbols between individuals and how these are produced and repeated creating shared knowledge and cognitive understands that underpin institutionalism (Scott, 2008).

These philosophies and theories influenced the development of the sociological perspective of organisational institutionalism from which this thesis is drawing its philosophical foundations.

4.3 Theoretical lens

This section will explore the theoretical lens through which this thesis is being conducted. The overarching theoretical lens is that of interpretivist organisational institutionalism and specifically institutional work theory and institutional change. Organisational institutionalism and institutional work theory were discussed in detail in Chapter Two. This section will critically explore the philosophical underpinnings from a research methodology perspective.

Whilst organisational theory was predominately influenced by modernism and the search for objective truths, other disciplines such as social psychology and cultural anthropology were exploring subjectivity and interpretation. Suddaby and Greenwood (2009) outline four different perspectives related to institutional change research; multi-variate, interpretative, historical and dialectical or a combination.

Multi-variate is quite a blunt instrument in that it can demonstrate the evidence of change but does not capture the subtler processes that the outcomes had depended on (Suddaby & Greenwood, 2009). For example, it would be possible to research the impact of the Hospice Enabled Dementia Care report (Hospice UK, 2015) by asking how many hospices changed practice due to the report and the number of patients with dementia supported before and after the report. However, this approach would not help understand the thoughts of hospice teams around this change, it would not explain the extent the change was a full or partial adoption or whether it impacted how staff or volunteers made sense of their changing roles or environment. Therefore, this perspective would not help address the research question at anything other than a surface level.

A dialectical approach is born out of Marxism and critical thinking and is interested in issues of power and hidden agendas (Suddaby and Greenwood, 2009, Seo and Creed, 2002). This perspective goes beyond the functional approach of the multi-variate method in that it recognises issues of individual action and cognition. This approach does have something to offer in relation to changes within hospices and there are comments within the data transcripts that would fit with this perspective i.e. the suggestion that some doctors are actively working to maintain institutional norms around specialist palliative care. This approach would focus on theory relating to role identity, professionalisation and power. A dialectical approach would be a very narrow view of the issue and not address the research question, i.e. the thesis is not an exploration of the role of

professions in driving or blocking institutional change. Whilst there may well be an element of power and hidden interest impacting hospice adoption of services for people with dementia this isn't the focus of the research.

The historical approach is of interest as it recognises the institutions individual journey and implies a more chronological approach to understand institutional change. Hospices originated at a point and time in history around a specific disease that was current and prevalent where the existing health system did not appear to have a solution that was deemed acceptable by people such as Dame Cicely Saunders. Another key moment in hospices history was the 'specialisation of palliative medicine' in 1987. Of course, whilst not yet history, the issue of dementia, its prevalence and the lack of an adequate solution may well become part of the future history of hospice. David Clark (2016) used a historical approach in his book 'To Comfort Always: a History of Palliative Medicine', mapping key stages in the development of the medical specialism which interfaces with the history of hospice. The history of hospice helps describe how the norms, processes and behaviours that influence the ability for an institution to change have arisen.

An interpretive approach is the second most commonly used method focusing on how the institution is experienced by people involved with them (Suddaby and Greenwood, 2009). Selznick (1957) believed that institutions are 'infused with value beyond the technical requirements of the task at hand' and that organisations 'are as likely to adapt in ways dictated by societal concerns – such as conformity with culturally prescribed norms – as they are to change in ways that might improve productive efficiency' (Selznick, 1957 cited by Suddaby and Greenwood, 2009, p.181). The interpretive approach to institutional change centralises the acceptance that 'institutional change is *invariably* accompanied by shifts in meaning, understandings and values' (Suddaby and Greenwood, 2009, p.182). The attraction of this approach is that the issue of hospice services for

people with dementia does require an understanding of how the organisation and the field of hospice care is understood by people who are involved. There are many levels at which this could be explored that would be consistent with institutional work theory, i.e. individual, organisational or field. This approach is consistent with Mead (2015) and Blumer's (1969) view of society and self. Blumer (1969) proposes that actions take place within the social context in which it takes place based on how it is constructed due to how it is interpreted and that this is both at individual and/or group level.

This perspective is also consistent with what Hatch and Cunliffe (2013) describe as a symbolic approach to organizational theory, that 'organizations' are 'continually constructed and reconstructed by their members through symbolically mediated interaction e.g. organizational dramas; socially constructed realities where webs of meaning create bonds of emotion and symbolic connection between members' (Hatch and Cunliffe, 2013 p15). This links the 'self' with 'society' in that an individual's way of experiencing their environment can create connections and bonds with others creating symbolic connection. This is often apparent within hospices in why some members of staff choose to be employed by the hospice, why volunteers choose to give their time and how in some group work how family members and patients also create meaning and connections with each other. These meanings are part of the norms that are created within the narrative of hospice and influence therefore how people interpret and make sense of issues relating to change.

The primary perspective is that of an interpretative approach however, this will be combined with elements of historical. It would be impossible to understand the current issues without acknowledgement of the history that has brought the hospice movement to where it is today. It is tempting, out of sheer interest to dig into the history possibly more than is required to address the research questions and this will need to be guarded against.

4.4 Methodological approach

The methodological approach used in this thesis is an exploratory mixed method study with a strong qualitative bias. Creswell and Plano Clark (2011) outline key components of a mixed methods study including how the two forms of data can inform each other, combines them in a single study and that it is possible to give priority to either form of data.

A mixed methods study includes both quantitative and qualitative data and in a sequential study, one can inform the other. It would seem logical in a mixed methods study to baseline the number of people with dementia care receiving hospice support. However, the national data on the number of people with dementia cared for by hospices is currently unreliable (Vries & Nowell, 2011) and largely unavailable. In addition, the thesis is not seeking to demonstrate an increase in the number of people with dementia supported by hospice.

The quantitative data element is to understand the number of hospices who currently (or plan to) provide hospice care to people with dementia. The quantitative element is important as it provides some specific data that will inform both the interviews and the analysis. The qualitative element is designed to explore participant's views around the organisational issues impacting hospice care for people with dementia. In addition the qualitative element is also seeking to identify examples of institutional work.

An alternative approach would have been a purely qualitative study, given the population size it would however, be impractical to conduct semi-structured interviews with representatives from all hospices. A broadly qualitative survey could have been analysed using content analysis, but would not provide the sort of in-depth exploration of an interview. A mixed methods study provides the opportunity to do a combination of breadth of information from the wider population and some in depth analysis.

The in-depth analysis is consistent with Lawrence and Suddaby's (2005) view that there needs to be an exploration of people's experiences and perceptions. They argue that 'central to both theoretical and empirical examinations of organizational phenomena that adopt an institutionalist perspective is the idea that there are enduring elements in social life – institutions – that have a profound effect on the thoughts, feelings and behaviour of individual and collective actors.' (Lawrence & Suddaby, 2006, p. 216). Therefore, a predominately qualitative method is appropriate.

Institutional work has developed in terms of its position on the role of agency and recognises individuals as competent, reflexive and skilled (Lawrence and Suddaby, 2005). In the context of hospices, employees are skilled and competent and are acting within institutional boundaries whilst also reacting to significant external drivers creating challenges and shocks to institutional stability. Understanding individual's experiences and interpretation of challenges and issues relating to dementia, and how this issue is impacting the organisational field of hospice, is consistent with an interpretative approach. Dover & Lawrence (2010) highlight that institutional work theory has struggled to move from academia into management practice which has limited the ability to test concepts and theories. This study therefore adds to the empirical evidence of the implementation of this theory in practice.

4.5 Methods

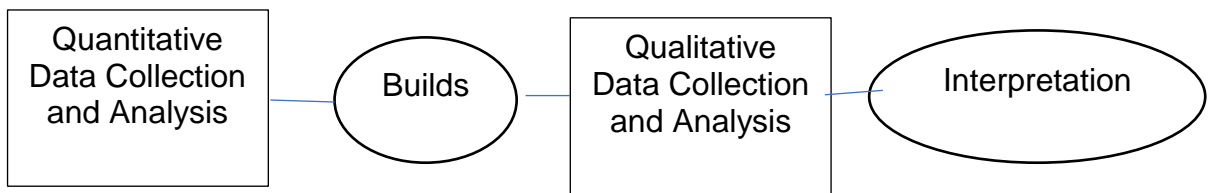
4.5.1 Research design

Designing a mixed methods study requires a series of decisions (Creswell & Plano Clark, 2011) which include:-

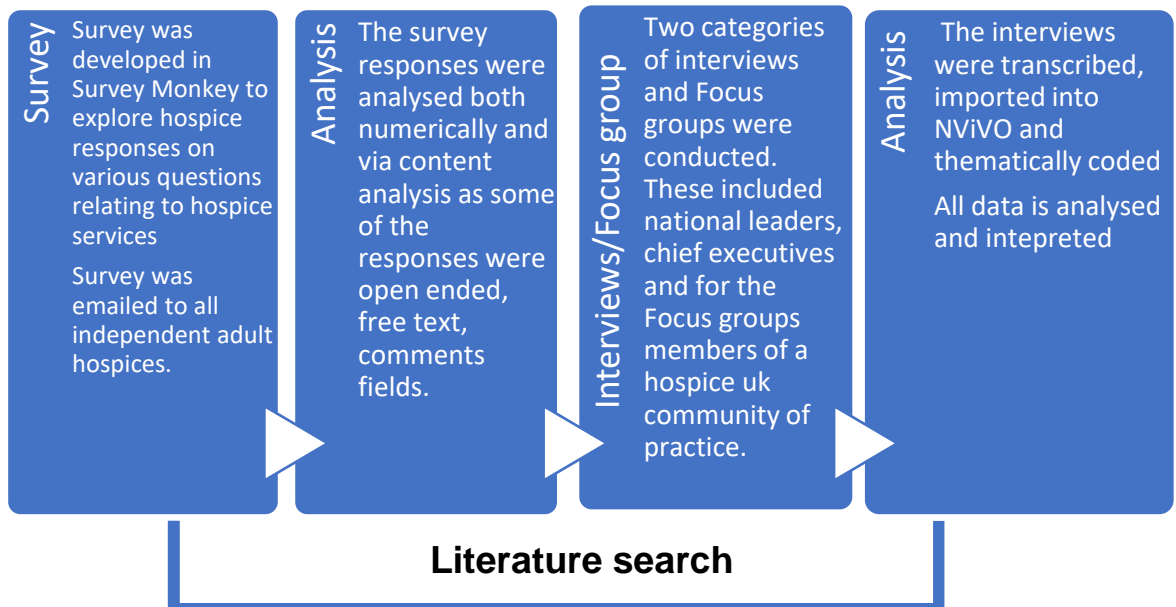
Table 4.2 – Key research design decisions

i)	the level of interaction	In this study there is a direct level of interaction. The survey which contains the quantitative element combined with a qualitative element informs the interview phase
ii)	whether the quantitative and qualitative strands are of equal priority	The qualitative phase takes priority
iii)	timing of the strands i.e. concurrent, sequential or multi-phase	This is a sequential study; the survey needed to be completed prior to the interviews
iv)	where and how to mix the strands i.e. during design, collection or analysis	The strands are mixed during the data collection i.e. the results of the quantitative strands connect the qualitative phase i.e. the results from the survey informed the recruitment of CEO interview participants and themes to explore.

The aim of the design for this research study is to explore organisational factors influencing hospice services for people with dementia. The study is therefore, an exploratory sequential mixed methods design. Figure 4.1 shows the high-level stages of this study, figure 4.2 shows the design path in more detail.

Figure 4.1 – High level, sequential mixed methods design**Design path**

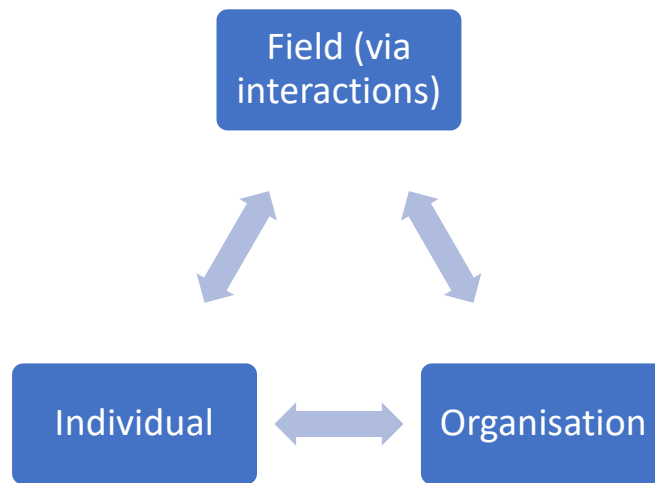
The design path demonstrates how the stages of the design relate to an exploratory sequential mixed methods design. The survey had to be completed and analysed prior to the interviews and focus groups taking place which could happen concurrently. The literature search was conducted during the first three phases of data collection and analysis, but prior to the final analysis and interpretation.

Figure 4.2 – Research design path

4.5.2 Levels of the application of organisational institutionalism and institutional work theory within the research design

The theory chosen for this thesis includes organisational institutionalism more broadly and then institutional work theory to focus on how individual acts can influence the ability to change. This enables analysis at field, organisation and individual levels. The aim is to apply the theory at three levels (field, organisation and individual), and in three different ways to address the research topic and questions.

1. The first is to consider the literature and determine how the theory can be applied to the hospice movement at field and/or organisational level, this will propose a model of hospice institutionalism.
2. The second is to use empirical data to evaluate Greenwood et al.'s (2002) model of institutional change (see Chapter Two). This model originated from some research conducted by Greenwood et al. (2002) and provides a useful comparison for the hospice sector.
3. The third is to use the empirical data to consider whether there are acts of institutional work and what they shed light on with regards to the issue of services for people with dementia. The application is based on the concept that individual agency can influence their hospice which in turn can influence the field via the variety of interaction that take place, e.g. the dementia community of practice. An individual can also influence the field directly depending on their role. That the 'field' can also influence an organisation which in turn can influence an individual and equally the 'field' can influence the individual directly. This can be seen figure 4.3.

Figure 4.3 – Multi-directional influence of institutional work

This application provides direct insight into the handling of the research questions which are repeated here for ease: -

Key question one - To what extent does the history, culture and identity of the hospice movement support or inhibit responses by hospices to the pressure (in policy, demographic changes and public expectation) of developing services for people with dementia?

- i. How are hospices defined?
- ii. How is the 'field' of hospice care (hospices collectively) defined and organised?
- iii. How are hospices, individually and as a 'field' reading and responding to internal and external pressures to develop services for people with dementia
- iv. What is the role of Hospice UK (the movement's membership organisation) in influencing hospices on the topic of dementia?
- v. How have hospices engaged with the dilemma of services for people with dementia and what are the associated barriers?

Key question two - Given this exploration of these organisational factors, what are the prospects for a (collective) response by hospices to the challenges posed by the demographic changes being faced?

This section has described the sequential mixed methods research design and how institutional theory is considered as part of the design. Section 4.5.3 will provide the chronology of the research.

4.5.3 Chronological stages of the research

The aim of this section is to describe the process and methods of research in a chronological order.

4.5.3.1 Ethical approval

The first step in conducting the research was to gain ethical approval (Appendix Two, page 250) which was achieved in December 2016 by both Keele University and from a hospice governance perspective, the hospice. A revision to ethical approval was achieved in March 2017, to add a focus group to the fieldwork (Appendix Two, page 252). The ethics pack included the ethics application form, a participant information sheet for each type of data method (i.e. survey, interview and focus group), consent forms and examples of the focus of questioning (examples of these documents are in Appendix Two, pages 253-266). There were no major ethical issues involved in the research, however, there were some considerations firstly relating to participant experience and secondly the researcher's professional role.

The research participants were all current healthcare professionals/managers. In that sense they were not a recognised vulnerable category. However, that does not automatically mean that participants might not be affected emotionally for professional or personal reasons. Therefore, exclusion criteria were set for anyone who thought they may be affected and anyone who was or had cared for a loved one with dementia over the past six months.

The other key potential ethical issue was one of existing working relationships and the researcher. The employing hospice was excluded from the study and therefore no one was put in the position of being interviewed by their own Chief Executive. In addition, hospices with which the employing hospice works closely were excluded from being interviewed. This was so that current and future working relationships were not impacted by a view that might be expressed by either party during the interview process.

Ethical issues were also considered in relation to data gathered and what would happen if participants changed their minds. The consent forms and the participant information sheets included what would happen in this instance. Where data was identifiable prior to analysis, participants could withdraw, and their data would also be withdrawn. Focus groups are difficult when it comes to withdrawal as the discussions and interaction of the group informs the data collectively. Therefore, whilst a participant can withdraw part way through or after attending a Focus group, their data cannot be withdrawn (Braun & Clarke, 2013).

4.5.3.2 Literature search

A review of the literature relevant to addressing topics associated with the research question is a critical component of the methodology. It is important to know what other people have written about the topic being researched. This included literature related to the topic and the methodology from a variety of sources e.g. books, journal articles and a variety of other material (Hart, 2001).

In the context of this thesis the literature included four key areas: -

- Background literature to provide a historical overview of hospice care and some current context
- Literature to explore the relevance of hospice care for people with dementia.
- Policy literature related to dementia care at end-of-life
- Empirical data from relevant studies

The literature search is described in detail in Chapter Three and a spreadsheet showing the search criteria and articles found is in Appendix One (pages 238-244) and therefore doesn't need to be repeated here.

4.5.3.3 Recruitment of participants

The recruitment of participants for each phase was slightly different: -

- i. Survey – a census sampling method for the recruitment of participants to complete the questionnaire was utilised (Daniel, 2012). The total population was a size that enabled all eligible hospices to be contacted. Eligibility criteria was determined to ensure that the sites chosen were comparable and relevant to the study. Children's hospices were excluded due to the issue of dementia not being a factor influencing a need in service redesign. NHS hospices or those part of a national charity such as Marie Curie were also excluded. This was because their strategy and decision making on the issue of dementia may not be locally determined. In addition, their funding mechanisms also varied in comparison to independent, charitable hospices. The researcher's own hospice was also excluded for ethical issues. The researcher is in a senior position and their views on services for people with dementia are well known and it would be unfair to delegate the survey to someone else who may feel coerced to complete it in a particular way. The eligible group for the questionnaire was 171 hospices.

Where possible the CEO was emailed directly, where this was not possible a generic email address was used acknowledging this was possibly likely to be less successful. Members of the target population were emailed a maximum of three times.
- ii. Focus group – the sampling method for this element of the research was convenience sampling, based on who was available at a particular point in time (Ritchie, et al., 2014).
- iii. Interviews – these included three distinct groups of participants: -

- a. National Leaders
- b. Chief Executives (or delegated person) who via their survey results suggested they were planning to increase services for people with dementia and
- c. Chief Executives (or delegated person) who via their survey results suggested they were not planning to increase services for people with dementia.

All of the interview participants were selected via purposive sampling. The national leaders were hand-picked, and the hospice Chief Executives (or nominated other) were selected based on survey results. The national leaders were people involved in national work or discourse on either the future of hospice care or their role with dementia. The purpose of the thesis is not to present an opinion on whether hospices should provide services for people with dementia, the research aims to discuss some of the internal and external organisational factors.

The aim behind the selection of the Chief Executives (or nominated other) was to select an equal number of people who were 'for or against' developing services for people with dementia. The aim was to ensure that there was balance in field data collected from individual hospices rather than evidence being outweighed by the number interviewed who were for or against.

The results of the recruitment methods are discussed in Section 5.3.

4.5.3.4 Data collection

Survey

This section aims to describe the rationale for selecting a survey and the method by which the survey data would be collected. The survey aimed to provide background data relating to hospice services for people with dementia. Data on the numbers of patients with dementia being cared for by hospices is not consistently available and therefore it would be of little value asking this question. Equally it would not add to addressing the research question.

As with most methods, surveys come with advantages and disadvantages. This method was chosen to gain background information from a high proportion of the population, which would inform the questions asked in subsequent interviews. The survey would provide empirical data on what individual hospices are doing in response to the challenge of dementia. The survey method also had the advantage of being inclusive and cost effective. A disadvantage of the method may relate to the level of detail provided in the responses (Denscombe, 1998). This was mitigated by having some comment boxes which would provide qualitative data which could also be analysed. Four surveys were delegated to other people within the hospice and it may be that the CEO and the respondent have different opinions about dementia. The main benefit of a survey for this thesis was that it would be possible to survey every local independent adult hospice.

After exclusions, as detailed in Section 4.5.3.3, there was a dataset of 171 hospices to survey. A sampling frame was created including the details required to send the survey (Denscombe, 1998). To create the sampling frame, a list of hospices was downloaded from the Hospice UK website and excluded those not relevant for the study, i.e. children's hospices, NHS hospices, the employing hospice and national charities. Hospices with more than one site which in effect created duplicate entries in the sampling frame were merged. The aim of the

survey was for it to go directly to the Chief Executive email addresses wherever possible, this information isn't readily available and was searched for on websites. For those where a Chief Executive email wasn't available the email went via a different route i.e. via the 'contact us' email address from the hospices' websites. It is recognised that the 'contact us' email approach might impact response rates.

The email included an invitation and the participant information sheet. Consent to participate in the study was contained within the survey which was designed using Survey Monkey, an online survey development tool. Consideration was given as to whether the best results would be via a web-based survey tool or a paper copy posted out which would have to be completed by hand and posted back. It was decided that a web-based survey would be easier to complete and analyse, although emails can get lost in busy inboxes. The survey results can be extracted from Survey Monkey and stored electronically on a secure server. A copy of the survey can be found in Appendix Two (page 265).

Interviews

Interviews are either structured, semi-structured or unstructured. Semi-structured interviews are, according to Braun and Clarke (2013) the most common method used in qualitative research. As the title suggests the interview has some predefined questions with some capacity for other issues to be explored. An unstructured interview has a list of topics and is 'strongly participant led' (Braun & Clarke, 2013, p. 78). The 'national leader' interviews were broadly unstructured whereas the CEO interviews were semi-structured. The reason for this was that the 'national leaders' held different positions and therefore their perspective would potentially differ to each other more so than the CEO interviews. The CEO interviews were designed to pull through some of the themes from the survey.

Interviews were perceived as an opportunity to explore experiences and perspectives from a variety of individuals on a one to one basis. Whilst being

time intensive for both the researcher and the participant it is an invaluable way of engaging in a conversation that allows the interviewer to check their understanding of the interviewees comments and ask follow on questions to explore points of interest for the research that might not come out of a survey or a structured interview with more closed questioning. This dialogue can reduce the risk of misinterpretation and researcher bias although does not completely eliminate it. The number of interviews was in part chosen due to the time constraints of the research study.

Recruitment for interview participants was discussed in Section 4.5.3.3. The interviews were digitally audio recorded, transcribed verbatim and imported into NVIVO a qualitative software analysis tool.

The types of areas that were explored in the interviews can be found in Appendix Two (page 257).

Focus group

A Focus group is a common method by which qualitative data is collected.

Ritchie et al. (2014) believe that 'the value of these methods is founded on the belief that participants are individuals who actively construct their social worlds and communicate insight about it verbally' (Ritchie, et al., 2014, p. 55).

Participants contribute to a group discussion interacting with each other socially, adding or questioning each other's comments, not just those of the researcher (Braun & Clarke, 2013). A Focus group has the advantage that it is more time efficient than the same number of individual interviews, however, groups dynamics may mean that some participants contribute more than others. Equally some participants may feel unable to participate if there is a perception of power within the group (Braun and Clarke, 2013, Ritchie, et al., 2014).

Hospice UK run a Community of Practice Group for Dementia consisting of circa eighty healthcare professionals interested in dementia within hospice care. This

provided an existing group that it was possible to engage with as part of the fieldwork. The Dementia Community of Practice are a group of healthcare professionals from different organisations; they know each other and would have built some trust together as part of their shared community.

Invitations and information sheets (see Appendix Two, pages 258-260) for the focus group were sent via the facilitator for the group as the researcher did not have access to the individual email addresses and for data protection purposes distribution via Hospice UK made sense. Consent forms were completed prior to the Focus group commencing. The Focus group was audio recorded and transcribed. For ethical issues the exclusion criteria included anyone currently or recently caring for someone with advanced dementia.

Whilst the Focus group would of course be biased due to the fact that participants were voluntary members of a dementia community of practice, this element of research was aiming to explore their perspectives and experiences of developing or attempting to develop and deliver services for people with dementia within their hospices. Whilst possibly biased in favour of dementia, their experiences might be positive, negative or a combination of both.

4.5.3.5 Analysis

The eight stages of coding and analysis described by Braun and Clarke (2013) were followed to provide structure to the process, these include:-

- i) Transcription
- ii) Reading and familiarisation
- iii) Coding (initial noting)
- iv) Searching for themes
- v) Reviewing themes and producing a provisional map
- vi) Defining and naming themes
- vii) Writing – finalising analysis (Braun & Clarke, 2013, p. 2002-3)

The data from the survey was exported from Survey Monkey into Microsoft Excel and Adobe PDF. The data from the interviews and focus groups was audio recorded, transcribed and imported into NVIVO a qualitative analysis software tool. The transcription was orthographic, i.e. everything was transcribed verbatim (Braun & Clarke, 2013).

The data was analysed using three methods: -

- a. Quantitative method – the survey results were analysed via descriptive statistics and charts to demonstrate the percentage and number of participants responding in a particular way to the question asked.
- b. Content analysis - this was used to analyse the free text fields within the survey, where the primary aim was to understand the quantity of the sample who responded in a similar way. Content analysis originated for use in quantitative studies however, has since developed into a widely used qualitative method (Hsieh & Shannon, 2005) as a way of quantifying the content of text (Denscombe, 1998). The method of using content analysis is structured. Data is categorised and coded and analysed in terms of frequency. Denscombe (1998) describes content analysis as a method that establishes relevance and demonstrates what is important. He also comments that content analysis is best used when 'dealing with aspects of communication which tend to be more straightforward, obvious and simple' (Denscombe, 1998, p. 169). The survey data aimed to highlight priorities to be explored in the interview and Focus group stages.
- c. Thematic analysis – this was used to analyse the focus group and interview data. Content analysis is less useful in dealing with text that requires subtler interpretation (Denscombe, 1998) and therefore a change of method was required to analysis the main elements of qualitative data. This history of thematic analysis is less clear, there are several analytical methods which involve coding into themes. There has been some debate

as to whether thematic analysis is a method in its own right (Ritchie, et al., 2014, Braun and Clarke, 2013). Thematic analysis is now widely recognised and utilised in qualitative research, although there are some variations in method. There are strengths and weaknesses of this method, whilst it focuses on cross cutting themes it doesn't provide an in-depth analysis of an individual participant's view like case study analysis would. The analysis can be inductive i.e. not informed by an existing theory such as would be the case in grounded theory; or theoretical where the analysis is conducted within the framework of an existing theory. Alternatives are 'experimental' analysis based on how the participant experiences the world or 'constructionist' based on how topics 'construct the world' (Braun & Clarke, 2013, p. 175). This thesis utilises theoretical analysis and is conducted within the framework of institutional analysis. Thematic analysis involves 'discovering, interpreting and reporting patterns and clusters of meaning within the data', 'the researcher identifies topics that are progressively integrated into higher-order key themes, the importance of which lies in their ability to address the overall research question'. (Ritchie, et al., 2014, p. 271).

The data and analysis was then used to inform the discussion and conclusions in Chapters Six – Eight. The data and themes were pulled together in the discussion rather than discussing each data type separately. The aim is that this adds richness to the discussion of a combined view, triangulating data from different sources.

4.5.3.6 Coding

Survey Coding

The free text data in the survey was coded by hand using different colour highlighter pens to determine different themes which were then counted to

determine frequency and therefore importance of the relevance of certain themes to the population group.

Interview and Focus Group Coding

NVIVO © does not analyse or interpret the data, but is a useful tool for coding data. There are a whole variety of reports that enables data to be presented, including word frequency maps. However, the researcher purely used NVIVO © to hold literature and transcripts and to code the interview and focus group transcripts. Once the data was coded, print outs of the coded sections by theme enabled the researcher to manage and stay immersed in the material.

The data was coded within NVIVO ©, data was highlighted and either added to existing themes or new themes were created, these are known as emergent themes (Braun & Clarke, 2013, p. 202). The themes were reviewed, adapted and clustered during the creation of a thematic map until some main themes and subordinate themes were created (a copy of the thematic map showing main and subordinate themes is in Appendix Three (page 270)). These themes were considered within the context of the theoretical framework (organisational institutionalism and institutional work).

Chapter summary

This chapter provides insight into the methodology both theoretically and practically used to address the research topic '**A mixed methods study exploring organisational factors influencing the development of services for people with dementia in English hospices**'

. The methodology was explained by using the following framework: -

1. 'Paradigm worldview
2. Theoretical Lens
3. Methodological Approach and

4. Methods of data collection' (Creswell and Plano Clark 2007, p39).

This format enabled a structured approach to describing the thought process behind the research methodology and design as well as providing a chronological view of what actually took place.

The next chapter will present the results from the fieldwork.

Reflection

Parts of this chapter were the most difficult to write, in particular the section regarding paradigm worldview. The learning curve from my Master's Degree to doctorate level has been significant. I hadn't previously had to consider where I am positioned when it comes to knowledge and how this feeds into theoretical frameworks and choice of theory.

There were many challenges in implementing the research design. The ethics process was lengthier and more challenging for this application than the first research proposal I'd submitted during and post progression. My supervisors were very supportive in keeping me calm during this process. The theoretical lens blended very well with my paradigm worldview and the theories that I was applying and I was pleased that it recognised the need to blend a historical and interpretive approach (it justified my excursion into the history of hospices!). The data collection methods were relatively straight forward in comparison.

5 Chapter Five - data collection results

The aim of this chapter is to review the results of the fieldwork. The chapter is presented in sub sections including a) survey, b) Focus groups and c) interviews.

5.1 Survey

This section outlines the results from the data collected from the survey which used Survey Monkey (a web-based survey tool). A copy of the survey can be found in Appendix Two (page 265). The survey was emailed to a population of 171 adult independent charitable hospices. Where hospices had multiple sites, the survey was emailed once. Where possible the CEO was emailed directly, not all their email addresses were available publicly, so in this case the invitation to participate was emailed via the general email address available on the hospice's website. There was concern that there would be lower rate of return, however, table 5.1 demonstrates that the return rate between the CEO group and the 'other' group was not significantly different. The response rate to the survey was eight-three, (47%).

Table 5.1 - Breakdown of survey response

Total population size	171
CEOs emailed directly	80
Emails to 'other'	91
% of direct emails to CEOs returning	45%
% of direct emails to CEOs not returning	55%
Emails to 'other' returning	58.2%
Emails to 'other' not returning	41.8%
Total number of respondents	83

Each potential participant was contacted three times, the invitation email was sent twice, and a final chasing email was also sent. As Denscombe (1998) writes, it is difficult to determine the causes relating to non-responses. It could be related to their capacity or willingness to complete a survey or could indicate a lack of interest in the topic of dementia. The number of responses are positive and perhaps highlight the importance of the personal contact via email rather than a general link in an e-news circular. Hospice UK's survey for the Hospice Enabled Dementia Care publication, received only twenty-five responses from the total UK hospice population (Hospice UK, 2015).

The survey results were analysed twice, firstly based on chart data from the multiple choice and closed questions; and secondly free text comments were themed via content analysis.

5.1.1 Quantitative survey results

5.1.2 Survey Results as charts

The charts presented in this section provide a simple, graphical way of demonstrating how participants responded to the questions. The content analysis of open text fields are discussed in Section 5.1.3.

Figure 5.1 - Was your hospice founded specifically to care for people with cancer or for a wider range of diseases?

81 of 83 respondents completed this question. This chart shows that most respondents believed that their hospice was founded for people with cancer and other diseases, not just cancer. Given the cancer dominance of the movement's history this response is interesting. If this is the case, despite the initial intention of the charity, the national statistics demonstrate that cancer dominates (see Figure 1.2).

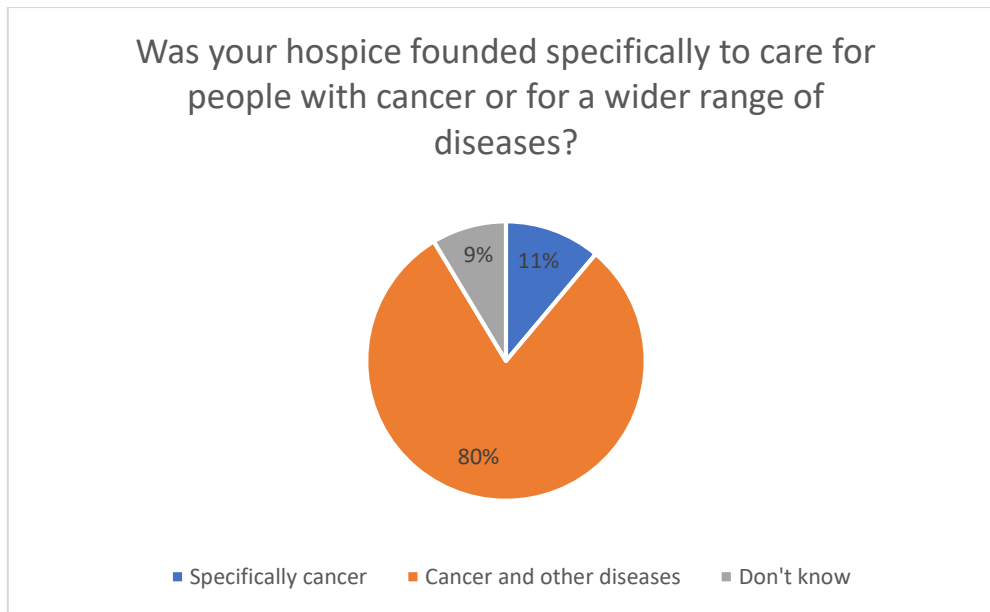


Figure 5.2 – Does your hospice provide care for people with a primary or secondary diagnosis of dementia?

All 83 participants answered this question. Figure 5.2 suggests that most participants believe that they provide hospice care for people with both a primary (this is the main diagnosis), or secondary diagnosis of dementia (i.e. the person has for example cancer and dementia is secondary to that). The question doesn't of course ask participants to quantify their response. It is not clear from the narrative response what exactly was meant by not applicable (N/A), it was meant to suggest 'not applicable' due to there being no service. Not being able to quantify how many patients is a limitation of the survey and is discussed in Chapter 8 in the section on limitations.

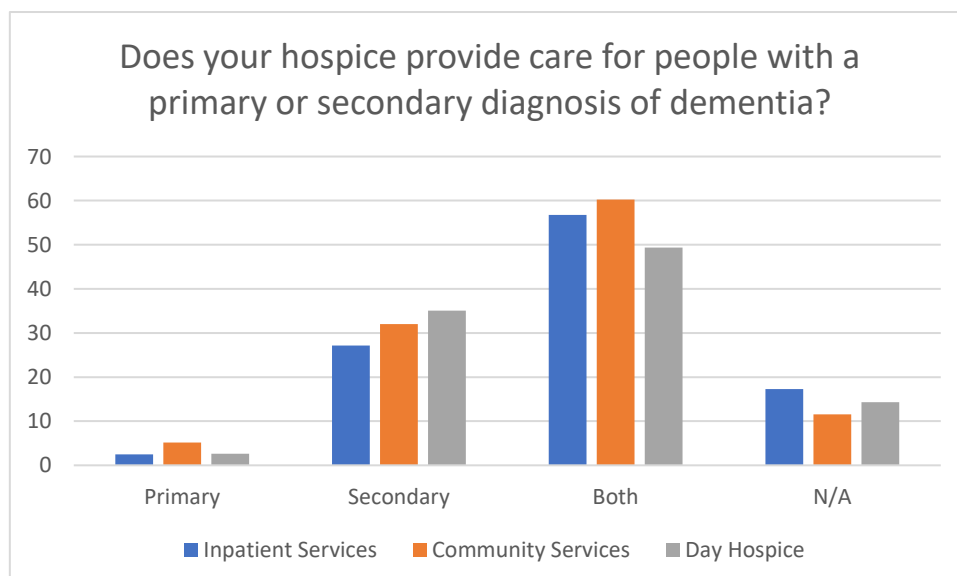


Figure 5.3 – If YES to question 5 (figure 5.2), for how long has your hospice provided services for people with dementia?

77 of 83 participants completed this question. This chart suggests that the majority of participants have supported people with dementia for more than five years which pre dates the Hospice Enabled Dementia Care publication (Hospice UK, 2015).

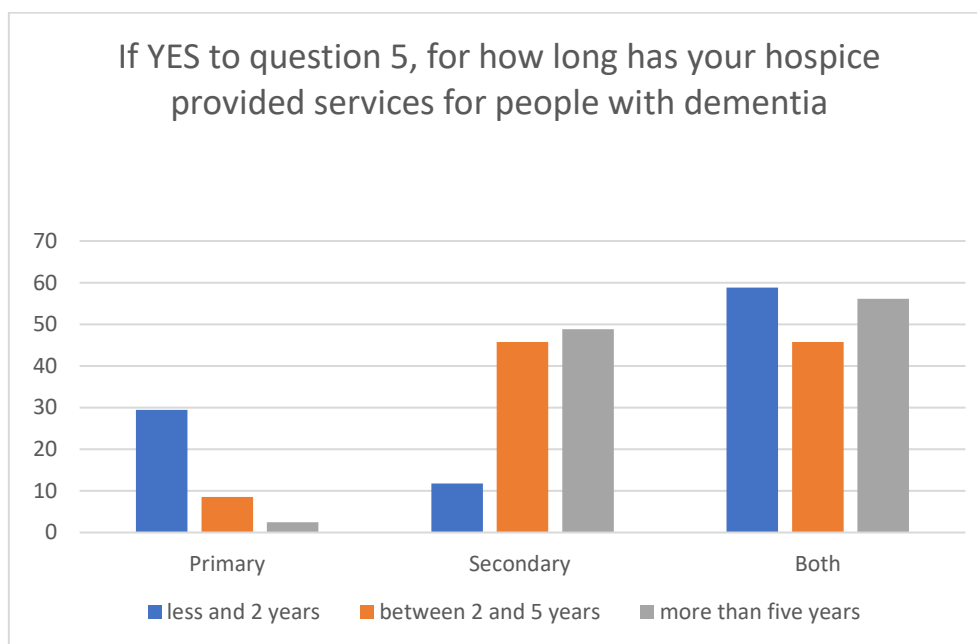
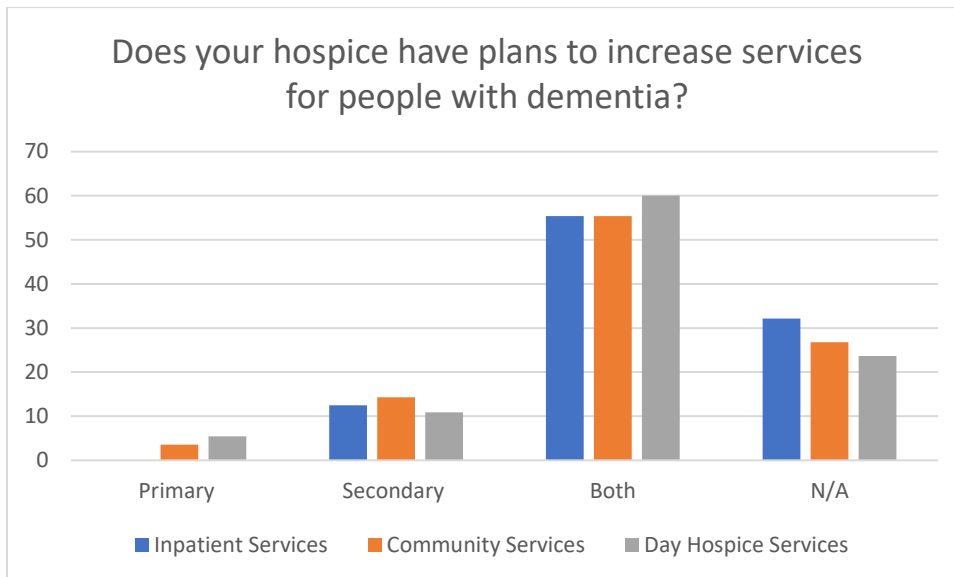


Figure 5.4 – Does your hospice have plans to increase services for people with dementia?

Only 63 of the 83 participants completed this question. These results demonstrate that most participants planned to increase services for people with both primary and secondary dementia across inpatient, community and day hospice services. The not applicable was supposed to indicate 'no plans' and reading the narrative comments, they would be consistent with that for example '*only if there is a demand for this. Currently no requirement to increase services*', '*no we have no plans to increase services specifically for dementia*'. Day Hospice appears to be where most services are expected to be with 60% of respondents indicating their growth will be in this area of service provision for both primary and secondary diagnosis of dementia.



Figure

5.5 – Do you think that hospices have a role in supporting people with dementia?

All 83 participants answered this question. These results demonstrate an almost unanimous response in the perspective that hospices have a role in supporting people with dementia. Views on what that role might be are discussed in 6.1.6 under the theme models of care.

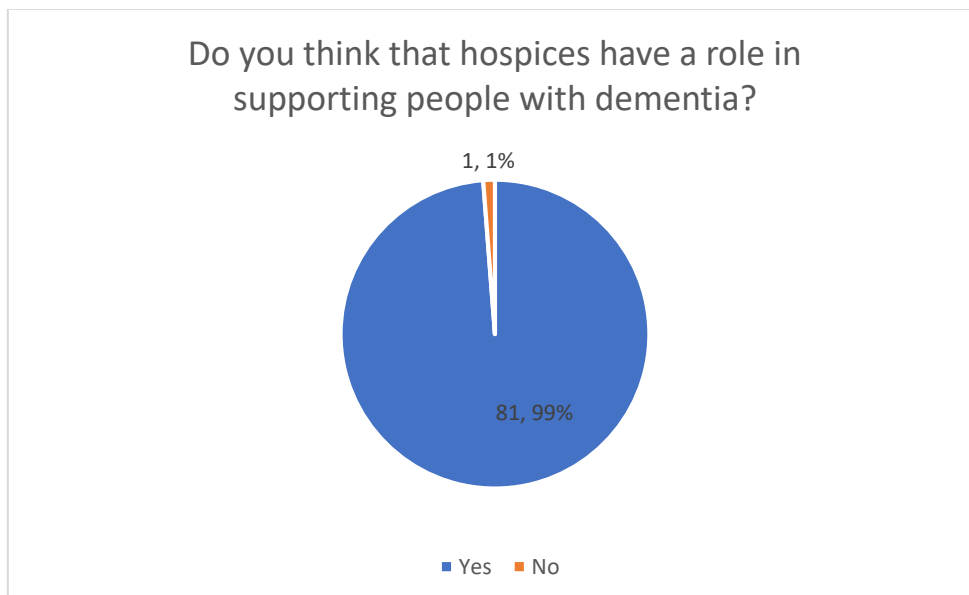


Figure 5.6 – In considering your response to hospice care for people with dementia has this started with...?

82 out of 83 participants responded to this question. Most participants had considered an approach to determining their strategy relating to hospice care, the

results being quite varied. 42.68% respondents had started with a strategic review of demographics and local demand.

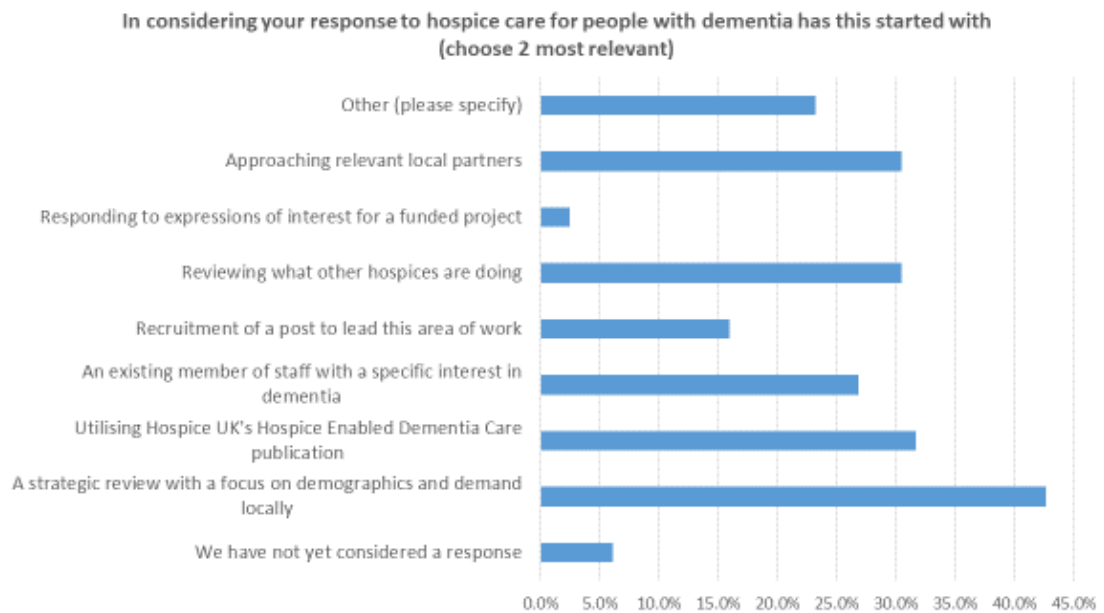


Figure 5.7 – What are the barriers to providing hospice services for people with dementia?

82 out of 83 respondents answered this question. These results are not surprising considering the practical barriers being faced by hospices. Only 6% (n = 5) suggested that services for people with dementia was a challenge to philosophy or strategic direction. This particular barrier is explicitly institutional in nature, based on norms, values and identity. Workforce skills was the largest response at 67.07% which is consistent with the themes across the other sources of data collection.

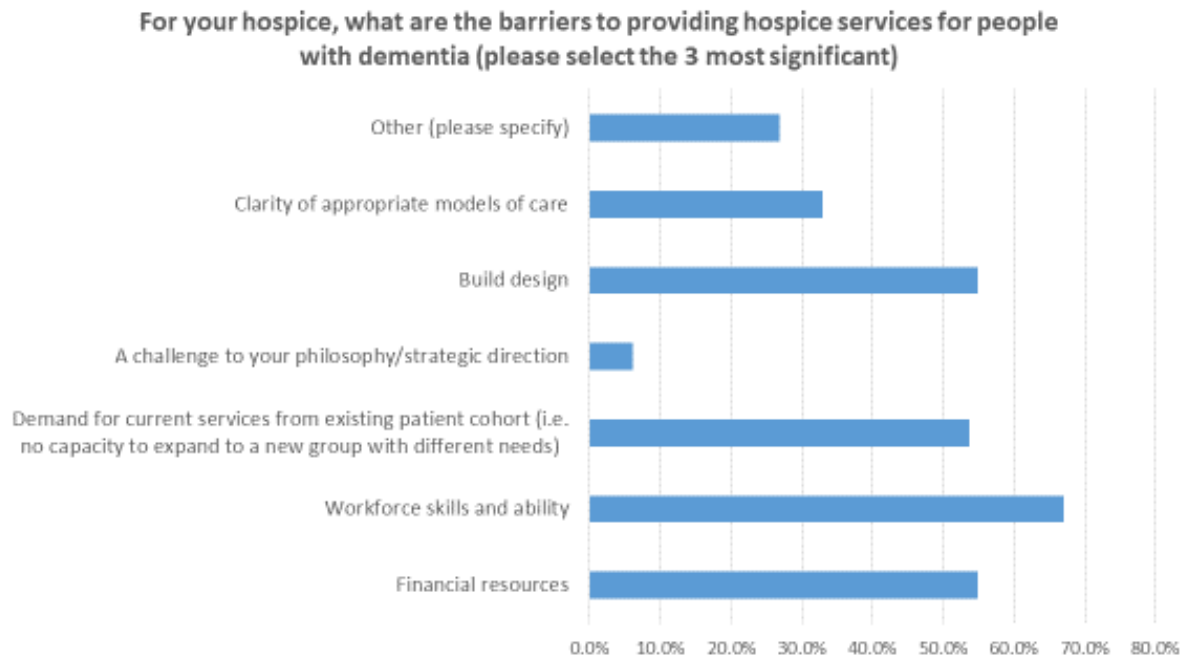
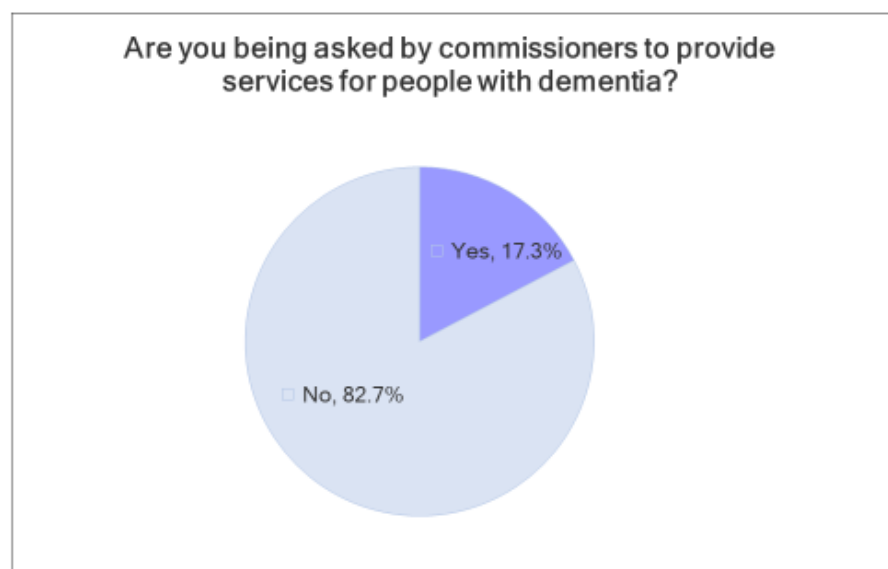


Figure 5.8 – Are you being asked by commissioners to provide services for people with dementia?

These results demonstrate very little external pressure currently, coming from commissioners. Therefore, the high level of respondents planning to increase services, are not been driven from NHS commissioning expectations but from some other driver.



In addition to the closed questions in the survey which were tick box or multiple choice, there was the option to add free text comments to supplement the answers. Section 5.1.3 discusses the data contained within open text fields within the survey.

5.1.3 Content Analysis

The free text fields were analysed using content analysis which is seeking the frequency by which similar comments are made to construct themes from the data (Braun & Clarke, 2013). To do this, similar comments were colour coded using highlighter pens, from these grouped comments themes were generated see Table 5.2, page 157).

The survey results are confusing and having presented them several times including to a meeting of the Dementia Community of Practice they remain so; some researchers might call this “messy data”. The results would suggest that the majority of hospices are already caring for people with dementia and not just those who have dementia as a secondary disease to cancer. Based on the survey results 56% (n = 23) of respondents had been providing services for both primary and secondary dementia for over five years with 46% (n = 16) providing inpatient services. These results are not consistent with the national data which demonstrate c. 80% of patients on inpatient services have cancer (Chapter One, Figure 1.2), although of course some may have a secondary dementia. If these survey results were accurate, the issue of dementia would not be such a significant ‘jolt’.

The survey did not ask respondents to quantify the number of patients with dementia as it is known that this data is either not available or is inconsistent within the field. So it could be that the respondents are answering that they do provide services but the numbers are small. Equally it could be that the respondents believe they do but this might not be happening in practice. In

presenting the data to audiences of people operating within this field, it was clear there was a disconnect between the results and actual practice. Further analysis of the data in these charts is discussed in chapters 6, 7 and 8.

5.2 Focus group

This section describes the results from the focus group. The focus group involved people who were part of a Hospice UK supported Dementia Community of Practice and therefore were likely to be advocates of services for people with dementia. However, the focus group aimed to explore some of the perceptions and barriers surrounding their work.

The first attempt at holding a Focus group was unsuccessful. Following an invitation being sent to the members of Hospice UK's Dementia Community of Practice, only three people could make the proposed date. Braun and Clarke (2013) highlight that disadvantages of Focus groups include travelling distance for participants. Therefore, a second invitation was sent out to the same audience, but this time scheduled to be at the end of one of their scheduled meetings. Eleven people took part in the discussion which was digitally recorded and transcribed verbatim.

The transcribed data was imported into NViVO © and coded. This involved selecting sections of text and allocating them to 'nodes' which is basically a term for themes. Once coded similar nodes are reviewed as data is consolidated into a smaller number of themes. Seven main themes with 21 subordinate themes (see Appendix Three, page 267) were identified during this process. In comparing these themes against those generated by the interview analysis, the main themes were the same and therefore consolidated into one list. The seven main themes are in Table 5.2, page 157. The data was coded twice, firstly for the themes originating from the data and secondly specifically looking for possible acts of institutional work. Therefore creating a theme of 'institutional work'.

Unlike content analysis, used in the survey, which focuses on the quantity of a view or comment expressed, thematic analysis seeks to interpret the views shared and consider them in relation to the theoretical framework used. This data will be further explored in Chapters Six and Seven.

The focus group included healthcare professionals who had chosen to be part of a discussion about their experiences of the dementia agenda within hospices. They were from a range of backgrounds and locations and included people who had been in hospice care for a long time in addition to people brought in with dementia skills. It was a good discussion with a good level of participation from everyone. Of course this group are biased in that they are committed to dementia care, however, it is their experiences, good and bad that were interesting to capture.

5.3 Interviews

This section describes the recruitment results and an extract of the data collected from the interviews. Interview participants were from two groups:

- Hospice national leaders
- Hospice chief executives (or delegated person – the person who completed the survey)

The hospice chief executive category then needed to be split into a) those 'for' increasing services for people with dementia and b) those 'against'.

Hospice national leaders (n = 5) were purposively sampled based on their known roles within the field. They were selected based on their national role in the field of hospice and/or due to being involved in tackling the issue of dementia. Being able to identify such leaders and being able to contact them personally regarding an interview, is one of the advantages of being an insider researcher. One person was both a CEO and a hospice leader (included in the six CEO participants).

The chief executive interview participants (n = 6) were purposively sampled from the survey results. The aim was for an equal number of participants. However, only one person explicitly stated that they were not planning to provide services for people with dementia. Therefore, it was necessary to select participants via a different identifying factor. The other factor within the survey that is relevant to the thesis is the extent to which providing services for people with dementia is a challenge to philosophy or strategic direction. Five respondents selected 'a challenge to philosophy or strategic direction', one declined to be interviewed, another provided limited services and therefore whilst possibly of interest would perhaps have less comparable views and therefore three were selected for interview.

To ensure categories a) hospices planning to increase and b) hospices not planning to increase remained even, it was also necessary to determine how to narrow down the number of category 'a' participants i.e. those in favour of increasing services for people with dementia. An even response between 'for and against' is explained in Section 4.5.3.3.

To do this, all hospices within the researchers own region were excluded. This was due to wanting to ensure that research participants could speak freely (Braun & Clarke, 2013). The list was narrowed down further by selecting hospices who had provided the full range of services for more than five years. The list was then given to the researcher's personal assistant to make three appointments based on what made sense logistically due to travel and diary commitments, one interview was conducted via Skype. In two instances the interview was delegated to the person who had completed the survey not the chief executive. Eleven interviews were completed, digitally recorded and transcribed verbatim by an audio typist.

The transcribed interviews were imported into NVivo © and coded in the same way as the focus group data. There were seven main themes and thirty-one

subordinates in relation to the interviews (see Appendix Three, page 267). In comparing these themes against those generated by the focus group analysis, the main themes were the same and therefore consolidated into one list in Table 5.2 (page 157). The data was coded twice, firstly for the themes originating from the data and secondly specifically looking for possible acts of institutional work. Therefore creating a theme of 'institutional work'.

The biggest challenge with the interviews was selecting the chief executives to interview, the survey results had been different to what had been anticipated, i.e. less people demonstrating concern or negativity regarding dementia. Working through justifiable criteria for selection was a concern and recognition that the number of interviews had to be what was reasonable for a part time doctorate student. There were hospices that were known to be doing some work in the field of dementia but they fell outside of the selection criteria so were not interviewed. This was a challenge as an insider researcher having knowledge but ensuring the method of data collection was justified and valid.

5.4 Themes

Despite the slight different methods of collection and analysis, the table below shows the themes from across the fieldwork therefore demonstrating similarities and differences.

Table 5.2 - Themes

Survey	Focus Groups and Interviews
Referral processes	Background
Workforce skills, capacity and culture	Culture (including equality)
Partnership working	Organisations
Equality	Workforce
Build design and becoming dementia friendly	Services / Models of Care
Having a 'specific' role – e.g. advance care planning, family/carer support, education etc.	Finance
Funding	Institutional Work

Chapter Summary

This chapter lays out the results from the data collection. The following chapters integrate the results with analysis and discussion. The results from the survey are more detailed being the quantitative element of the research. The results from the interviews and focus group as presented at theme level in this chapter with actual examples of comments being woven into the analysis in chapters six and seven.

Reflections

I'm sure it is the same for many researchers; I found it difficult to stay on track during some of the interviews. Some interviewees seemed more comfortable with a relatively unstructured discussion and then of course the challenge being to ensure that the interview was broad enough for depth but also focused enough to cover the information required for the research. I have continued to reflect on whether a further focus group was needed to balance out views, however, the question relates to the challenges faced by hospices not whether hospices should or shouldn't provide services. Given the survey results being nearly unanimous on this point, I am comfortable with the decision to use the Dementia Community of Practice as the audience of the focus group. A slight change in the research question however, may have resulted in there being less validity in the decision of a single focus group.

6 Chapter Six – organisational institutionalism - field level discussion

The two discussion chapters are split into Chapter Six dedicated to field level discussion whilst Chapter Seven focuses on issues relating to individual agency via institutional work and considers a model of institutional change.

The aim of this chapter is to consider the literature and data and determine what insights emerge as the lens of organisational institutionalism is applied to analysis of the hospice movement at field and/or organisational level. The chapter will propose a model of organisational institutionalism based on the current state of the field. It will present data and analysis at field level focusing on the relevance of organisational institutionalism and related concepts.

The survey highlighted that workforce skills and ability is the most significant barrier perceived by respondents, 67% (n = 55) based on the survey and between 59% and 75% if applied nationally. This was followed by finance, build design and demand from existing patient cohort which were all similar. 99% (n = 81) of respondents believed that hospices have a role in supporting people with dementia and between 55% (n = 31) and 60% (n = 33) of respondents replied that they planned to increase services for people with dementia. This increase in services is despite the fact that there were concerns around finance, build suitability and current demand. Adding to this that 83% (n = 67) of hospices were not being asked by NHS commissioners to provide additional services. There is nothing in any of the data to suggest hospices are considering dementia as an investment to raise additional funds or that they will withdraw services from other patients. Therefore, the drive to provide services for people with dementia is not coming from an explicit economic perspective but one that is sociological around equality, value and community.

Accepting hospices as part of an organisational field is useful in providing a new language to describe the group of individual organisations. The word 'movement' is still used to describe the collective of hospice organisations in today's narrative

which is understandable as part of the distinctive history, however, it does not fit with the current status of the field. Blumer (1969) cited by (Giddens & Sutton, 2013) describes four stages from social movement to institutionalisation as typical phases of organisational development (see Section 2.3), the hospice experience is consistent with this.

In understanding an organisational field, other concepts such as institutional change and legitimacy enter the discourse. Therefore, as part of this analytical framework, this chapter is organised to show the connection or integration of the data and the theory. The two perspectives outlined in the methodology (Section 4.3) relevant to this thesis are historical and interpretative, whilst predominately following an interpretative method. As identified by Selznick (1957) the distinctive history of an institution is part of its process of institutionalism.

6.1 Organisational field

Chapter Two described the criteria that Powell and DiMaggio (1991) apply to being an organisational field. This section will consider the data relevant to being part of an organisational field. This will include elements of history, themes around the hospice 'movement', the role of Hospice UK and the 'sociological jolt'.

6.1.1 History and the hospice movement

Despite the dominance of cancer, 80% (n = 65) of hospices stated in the survey they were founded for people with cancer and other diseases, with only 11% (n = 9) being specifically cancer and 9% (n = 7) not knowing. However, the literature is clear that hospices originated out of a response to cancer (Du Boulay (2007), Clark (2003, 2016) and the data from NCPC (Figure 1.2, page 13) also exposes the extent of cancer dominance as illustrated by:

'the commission heard a passionate and convincing call for the engagement of hospices in end-of-life care for people with this condition

[dementia] given its high symptom and disability burden and the challenges faced by carers' (Help the Hospices, 2013, p. 17)

If you don't have cancer, you're almost treated as a second class citizen' (Help the Hospices, 2013, p. 17)

There are also examples within the qualitative data relating to the cancer dominance...

I was aware of the cancer dominance because I'd actually come from an oncology background' (I1)

'all cancer and erm, but, they had 10% of patients with MND'...'so that blew my head, thinking that hospice is not just about cancer' (I10)

Historical context is relevant to the development of hospice care and the organisational field. Cancer was the primary cause of death at the time Dame Cicely Saunders was developing her vision, she spoke at oncology conferences and oncology doctors would spend part of their training in hospices. When palliative medicine became a specialty, therefore it originally attracted people from oncology, not from cardiology, respiratory or dementia. St Christopher's hospice was predominately cancer and had legitimacy based on Dame Cicely Saunders work, inspiring other hospices to be similar.

There are people who join hospices, the researcher being one, who did not know the history and connection to cancer, new people joining the movement, not steeped in its history, may be part of the questioning about its future, one of the interview respondents commenting

'I suppose strangely I never really erm twigged that there was this strong link with cancer, I mean I suppose I might have done if someone had asked me directly, but I just genuinely thought it was care for the dying..... I didn't think it was particularly any particular condition, so actually when I

came in, saw the stats and also hospice are still saying 85% cancer erm I was surprised actually'. (18)

There is also some insight into the role of Dame Cicely Saunders as an institutional entrepreneur and that it is cancer for which there is a commonality of practice, i.e. where hospices are isomorphic.

'I'm not sure we are a movement anymore at all er..I think we were when Cicely was a) alive and b) her teaching was very erm... considered to be the blueprint for how hospices should develop, she also was a seriously clever, thoughtful woman and erm we were right to listen to her, she had a clarity that very few people clinically have ever had since, but, she very much focused on cancer and so I think if you look at the way you treat someone with pancreatic cancer in your hospice and in my hospice and in someone else's hospice it would be pretty similar, it's evidence based and we follow a very, kind of clear model etc etc, erm... we are all slightly different now and we love being different erm.....so it's not surprising people will have very different responses to a new thing and we don't have a very strong, what Cicely had, now about say dementia' (12)

The comment above and the three below, show a recognition that the hospice movement has stalled – or in the context of this theory, institutionalised. The comment also demonstrates a tension regarding the extent to which hospices may want to remain similar, particularly if that similarity is at odds with the views of institutional entrepreneurs. The language of movement conjures up images of social action – but at organisational field level there doesn't appear to be a compelling new narrative...

'noise from outside of the hospice sector that said you are last generations solutions to the problem, you are irrelevant, you are dealing with a tiny proportion of deaths.....and erm it's not specialist actually it's the sort of pillow fluffing and the cold compress on the forehead and lots of teas and coffees and cake and isn't that nice but actually the real work is going on in the NHS and you will die when your generation of funders die.... wasn't it a lovely idea erm but your times gone because the hospice movement was a movement when it was building and erm creating new models of care.....I want the hospice movement to move again, I don't want hospices to die out, get sold off, become community centres and then in another 10-20 years' time somebody comes along and says we've got to do something about the next generation of palliative care. So we need to get out of our comfy cosiness and start moving again which means we are going to be disruptive again if we want to be a movement, which means that we are going to say things people don't always like.' (18)

'we're a movement who as you say kind of evolved really hasn't it so you've got people who have kind of started off in the hospice who have been there for quite a long time who don't question anything, who are not connected to the real world, who don't understand what the pressures are in the NHS for example' (111)

'the movement element might get smaller, but I think it will get a bit more radical' (19)

Such frustration demonstrates that within the data sample there are people who believe in the need to change and shift the direction of the organisational field. There was no evidence to suggest that any single organisation who participated was planning to go in a radically different direction on their own, reinforcing the security of being part of organisational field and the need for legitimacy. Working

alongside partners was considered a way of evolving 'safely' or configuring the field differently which was seen as a possible future for the movement ...

'there are some that get the whole thing that we can't do what we need to do unless we work with other people, unless we work in partnership and we're not precious and we're generous with our response whoever that needs to beI think there are others who don't think like that' (111)

'I think the overall principles are that we want to provide palliative across the board and people actually choose to do it differently and as long as that overall aim is that we are supporting people to live and die well, support their families we've got that overall aim. I'm a big lover of diversity, that's me, because I think, what is it different people can deliver, people can deliver different things as long as you're part of an overall jigsaw and not that bit that's outlying' (11)

'I don't know whether it would be fragmentation or just growing expertise but I think certainly in areas of the UK where there are several hospices close together erm expertise should be channelled, so I would see in any area it would be good to develop some expertise around heart failure or dementia, that doesn't mean that patient only has to go to that hospice' (19)

There was recognition in the data that belonging to an organisational field (Powell and DiMaggio, 1991) has certain responsibilities and a tendency to value isomorphic behaviour (i.e. similarity of form or service offer). Examples of this include:

'I think it always needs to be in your mind when you're running an organisation and you're part of a national movement erm you can't have us all going off in completely different directions cause actually that doesn't help the key messages that we're all trying to share about hospice care' (17)

'I welcome the stuff that comes out of Hospice UK erm because again, that is, that helps you with your own organisation's strategy and future of what you want to do and it helps you to share across the sector and I think that's absolutely vital, erm we need to work far more collaboratively and not in silos erm because we're all or less like you say we're all more or less providing very similar services to our populations' (I5)

There are also examples that suggest that hospices don't consider themselves as similar:

'I think there's loads of hospices out there that are not forward thinking that are....only looking internally, only look at themselves, probably quite a few, not, not many but a few believe hospice care is about beds' (I11)

This section highlights the influence of hospice history such as the role of Dame Cicely Saunders and the context that influenced cancer dominance. It also examines the current discourse that exposes certain tensions/concerns around the role of hospices as a 'movement' and the benefits and constraints of being part of a highly organised organisational field. The next section will therefore focus on the role of Hospice UK which provides the organising forum and point of representation for hospices as a collective within the field.

6.1.2 Hospice UK and legitimating actions

Chapter Two provided evidence that hospices are both independent organisations and members of an organisational field (Powell and DiMaggio, 1991) and that Hospice UK operates as a meta-organisation (Ahrne and Brunsson, 2008). Hospice UK's role is to represent its members views, and support hospices in a variety of ways, including providing information on issues that might influence the movement. Hospice UK in addition to the NHS, the Care Quality Commission and the Charity Commission can act as a legitimating organisation (George, et al., 2006; Trank and Washington, 2009). Legitimating

organisations can influence the organisational field by promoting particular views and attempting to influence members decision around practice.

Hospice UK, as the national membership body, can legitimise particular views or strands of work, for example publications such as Hospice Enabled Dementia Care (Hospice UK, 2015), grant funds specifically for non-cancer (there was a grant funding round in 2015 specifically for dementia) and use of events such as conferences as field configuring events (Hardy & Maguire, 2010).

Hospice UK attempted to influence hospices via the publication of Hospice Enabled Dementia Care (Hospice UK, 2015). In the survey 31.7% (n = 26) respondents answered that the publication was referred to when considering their response to the development of services for people with dementia, this was the second highest response after a strategic review focusing on local demographics. There were also comments in the qualitative data consistent with that view, although not universally.

'That [hospice enabled dementia care (Hospice UK, 2015) was a really important piece of work because I think that it in a very basic way helped hospice that had been too frightened even to think about it to see that they could do it incrementally' (I1)

'We've not really looked at Hospice UK and what they recommend.....I don't know what Hospice UK's approach is on dementia, they've done some publication around it haven't they?' (I6)

The relationship between individual hospices and Hospice UK varied. Research participants that were supportive of the input of Hospice UK made several comments, however, there were others clear about their boundaries and inability to direct individual organisations. There is a fine line between appearing to legitimise and directing.

'Hospice UK is a membership body, its members are individual charities.....it's not up to Hospice UK to direct hospices to get involved in dementia care most definitely it's not because it may not suit each individual hospices' circumstances'. (14)

'Would hope where Hospice UK would come in is that they would help hospices challenge the evidence for why they are making certain strategic decisions'. (13)

'The whole purpose of Hospice UK is a collaborative of all the hospices, the things that we can do once rather than a hundred and twenty times, it's more efficient to do it that way' (18)

'yes I think Hospice UK has a responsibility because they are the national voice and they need to be trying to pull out good practice and great examples from all of their hospices' (17)

In proposing or suggesting change, Hospice UK cannot legitimise particular actions or strategies in any functional sense, they cannot apply sanctions in the way the Care Quality Commission could or withdraw funding how the NHS can, also both legitimising organisations. The lack of sanctions reduces Hospice UK's power and influence as a legitimising organisation. It can influence hospices at an individual and group level, the Dementia Community of Practice being an example of this. Whilst bringing together a group of practitioners working in dementia within hospices is a useful act, it is also supporting legitimisation and encouraging internal 'institutional entrepreneurs' to continue in their disruption of the 'cancer dominant' nature of hospice (Coule and Patmore, 2013; Garud et al., 2007).

Hospice UK has influenced the debate around hospice care and dementia specifically via the Hospice Enabled Dementia Care publication (2015) and supporting the Dementia Community of Practice. This is evidenced by the 32% of survey respondents who cited that they had used the Hospice Enabled Care

Publication (Hospice UK, 2015) to help determine their strategy. However, work is at the margins and isn't yet challenging the traditional nature of hospice care.

6.1.3 The sociological jolt of dementia

Greenwood et al.'s (2002) model of institutional change starts with a 'precipitating jolt' something that can 'destabilize established practices' (Greenwood et al., 2002, p. 59). These jolts can be social, technological or regulatory. This research is focused on the sociological jolt of dementia. The literature in Chapter Three, exposed the significant 'jolt' that dementia is having across health and social care for example; people dying with dementia on acute wards, symptom burden, lack of access to palliative care and the challenge for hospices to engage (Help the Hospices, 2013).

The qualitative data evidenced the awareness of the demographic changes creating the 'jolt' that made the question of dementia relevant for hospices. There are many comments in the data relating to this theme, a selection are included below;

Focus Group

'more and more people are being diagnosed with dementia so it means more will die with a primary or secondary diagnosis of dementia so we have to adapt ourselves to a new reality' (FG M)

'there's no escape and I think that hospices that don't recognise that, I think, I think they would be at risk' (FG F)

Interviews

'I think dementia has been absolutely huge, I mean we've had things like CJD and AIDS which were thought to be a great tsunami but ended up not being such a you know.... such a big thing, they found treatments for that so I think dementia is the big thing that actually at the moment we have not you know any treatment forresearch shows or UK polls show that dementia is feared more than cancer' (I10)

'I'd like to think that it's hard not to do anything when you know it's becoming prevalent in your society, we're being told from so many avenues that this erm disease is going to have a big impact on us all you know within the population either we'll know someone with it, we'll be caring for someone, extended families are going to have more challenges so I almost think you can't avoid it' (I7)

'I'd like to think that er generally hospices are more aware of their populations than they have been historically, I think we are already beginning to see the impact of the older population.....I think even if hospices have er... wanted to close their eyes to it, it's becoming ever more impossible to do that' (I2)

This data shows that participants in the research recognised the scale of challenge, societal impacts of dementia and the need for a response.

6.1.4 New and old institutionalism and barriers

As discussed in Chapter Two, hospices fall into both old and new institutional theory. This because of its history i.e. arising out of a social movement, its relationship with the NHS, the specialisation of palliative medicine and its relationship with its local community resulting in volunteers and voluntary income. This section considers discourse within the data that demonstrates this 'push – pull' between theoretical stances. Doing this will focus on themes relating to

barriers to providing services to people with dementia and the extent to which they are institutional.

The survey asked whether respondents thought hospices had a role in supporting people with dementia, 99% (n = 81) replied yes. This question had 79 participants commented in the free text field, the most out of the questions asked. The content analysis showed that of the 79 people who made comments, 28 people (34%) added free text felt that the role hospices had to play was a specific element of care such as advance care planning, support for families or care at the very end-of-life. Of the 28 participants who commented, 24 (86%) believed that the response was simply a matter of equality.

6.1.5 Equity

The theme of equality was clear within both the focus group and interviews with some strong views expressed on access to hospice services for people with dementia;

Focus Group

'It also gives them the choice for them and their families, the same choices as everybody else in the population, they should have the right to be able to die and to be able to receive the care where they want it, it should be us now that have to adapt to them because, regardless we've.... everybody is living longer' (FG F)

Interviews

'for me this is an equity argument so actually I don't think it's something I need permission from the trustees to do because we're here to serve people with terminal illness in XXXXXX and dementia is one of those illnessesif my trustees started to question it then I would immediately say well this is an equity issues erm so and I, my argument would be well, perhaps we've seen too many people with cancer.....as I say it's an equity issue for me that's, as far as I'm concerned that's the bottom line, why would we provide services for people with cancer and not for dementia' (I11)

'we won't exclude them erm we would never do that I think the sort of philosophy of hospices is about that care for everyone that's got a life limiting condition and you don't discriminate just because they've got dementia.....I would be embarrassed, I couldn't work for somebody that excluded people because they had dementia' (I5)

There was only one negative comment on the issue of equity.

'I don't think this comes down to our human rights debates....we need to have some reality and some common sense creeping into the debate er and the reality and the common sense is the hospice movement provides excellent palliative and end-of-life care at the moment to those to whom it can..... the can is important in that you're not going to compromise the sustainability and survivability of your charity just because someone says oh it's individual patients' human rights to have hospice care because they've got dementia, that opens up the road to ruin for the whole hospice movement'. (I4)

This negative comment is consistent with one article found in the empirical literature search, where Becker (2017) also outlines the economic challenges hospices are facing and contests that 'political will is simply not there and never

will be'. He does not believe the government would divert funding from cancer to other disease groups and that meeting the challenge of non-cancer hospice care would 'mean a paradigm shift in our cultural thinking and health priorities' (Becker, 2017, p. 472).

The positive comments on equity, regardless of how realistic they may be, demonstrate perhaps what could be described as the vocational calling by hospice leaders to deal with dementia, as mentioned at the beginning of this chapter. The increased involvement that hospices are planning to have in this area of practice, is not being driven economically. One final comment on this theme is:

'we're all human beings, we all have families, we all have communities so this is happening to us as well as us helping other people that it's happening to and we're all living in the world and we're all affected by relatives who have dementia and friends and other families who have dementia and I think hospices are doing it because they genuinely recognise that it's the right thing to do'. (18)

For these participants, they are being driven by change and social action rather than persistence of a traditional norm.

The equality of access argument is a thread in the policy literature, however, the question is, what this actually means in practice. The empirical literature also had examples of equality but recognised the challenges in practice. Willis et al. (2014) proposed a 'moral compulsion' and 'fairness and justice' (Willis et al., 2014 p. 121, 122) which is behind the hospice movement's agenda to increase services for non-cancer patients. This is consistent with what the fieldwork data indicated.

Equality could mean dementia patients accessing services designed for people with cancer, or it could mean the development of new services. There are then the practical questions of how will equality be funded and if there is no more money is there an impact of equality on other groups of patients. It is some of these questions that drive the debate on models of care.

6.1.6 Models of care

This theme feels more aligned to new-institutionalism which is interested in the tendency to similarity among organisations in a field. Less about norms, attitudes and beliefs, and more about classifications and routines as the nature of cognitive understanding (Powell and DiMaggio, 1991). Disruptive acts of institutional work become essential, otherwise new models would not be defined and tested to the point they become a 'necessary' means of ensuring organisational legitimacy. The data shows that a tipping point of change, or demonstration of technical viability (Greenwood et al. 2002) has not yet been achieved.

The survey results demonstrated a lack of clarity; half of the respondents stated they planned to increase services, and these responses were split evenly across inpatient services, community services (which would include support into care homes) and day services. There is a concern for people with dementia about a change of physical environment and a lack of clarity in the literature that an inpatient stay might be a suitable service to offer (Section 3.3.1, 3.4.1) Those hospices who responded in the survey that they believed hospices have a specific role, shared their view with other participant's comments in both the focus groups and interviews. The lack of clarity of models of care or the position of hospice care for people with dementia was also a theme in the literature both policy; empirical studies and narrative related to the applicability of hospice care for people with dementia. Supportive data included:

Focus Group

'I think the barriers that I have found within my job role in the last 2 years is battling to get some changes within the hospice erm how the hospice has historically managed their patients' discharging plateaued patients we don't discharge the dementia patients and erm you usually don't have long term patients hospice patients but dementia patients are long term potentially erm and it's just about tailoring and meeting the service requirements erm

but you can't lump them together with your regular community patient caseloads so it's about recognising and managing the differences' (FG F)

'we've recently moved to a very new model of care in the last few weeks in fact erm which is very much a kind of time limited intervention with people and then people move into a kind of self-management and call us if you need us kind of thing and I'm not sure how that applies to dementia, it might apply very well to er cancer patients or somebody with other long term conditions but how does a dementia patient self-manage' (FG F)

Interviews

'I think that's the other thing, we don't know how to measure success with people with dementia, when people die with dementia in XXXXX we're just really grateful if they've died without running away, er their families are in one piece and the staff aren't too distressed by somebody who is up and out and if they haven't got into somebody else's bed or left a big poo in someone else's toilet we're even really more relieved, that's hardly a criteria for success' (12)

'I was trying to impose a specialist palliative care model that'd been developed in cancer onto you know people with dementia.....you know it's the danger of how far the hospice has aligned itself to cancer' (110)

'I think we're stumped, absolutely stumped.....they're not very biddable you can't negotiate....er the need for constant attention and stuff makes us feel uncomfortable because we can't meet that demand or we would feed bad if we can't and hospice nurses and hospice, you know er we're not used to saying no, we're not used to rationing. So I think it is a very new strand of care er.. and there was this concern that can we meet it and we're so used to good feedback.....it's probably a sense that well this is a bit too hard, too uncertain, unknown, we can't quantify how well we're doing'. (13)

The theme relating to models of care, also embraces the hospice movement's work with care homes. Many hospices have traditionally supported care homes via community nurse visits or via education programmes. Due to the demographic challenges and social care environment, 70% of people living in care homes have dementia (Alzheimer's Society, n.d. i), most people with dementia will die in a care home or in hospital. Care homes were discussed at various points within the fieldwork, this is not unexpected given both the prevalence of dementia in residential care and hospices' existing relationships with many care homes. However, there is also an issue relating to professional identity, status and care homes:

'I think identity is important because a lot of people identify a care home as being a natural institution for someone with advanced dementia and of course there are many people dying with dementia in care homes, so there is a fear in many hospices, you see it again and again if somebody has a very long admission erm will be labelled as a care home if we look after too many people with dementia' (I9)

'I think it wasn't there before, I also think the care home population, the care homes organisations were out with the NHS..... we did it [palliative care] to community, we did it to hospitals we didn't think of care homes until you know perhaps 16 years ago erm but also they, people in care homes unless they had a really complex cancer patient I don't think they realised they could call on our services'. (I10)

These two quotes are an important contribution to understanding the make-up of the organisational field of the hospice movement and the way hospices could potentially 'duck the question' or take a secondary role close to their 'distinctive competencies' in palliative and end of life care – perhaps through outreach rather than beds or by the concept of decoupling (Section 2.2.6 and Figure 6.2, page 188).

Several comments were quite practical, e.g. considering the best use of hospice care for people with dementia. This theme blurs into the theme around workforce and professional identity, workforce capability and capacity was perceived as the biggest barrier in the development of hospice services for people with dementia.

Empirical studies raised similar issues that span models of care and workforce e.g. lack of certainty around disease trajectory, boundaries between providers, dominance of the medical model, preconceptions of when hospice care applies or that a referral means 'giving up' (McCaughan, et al., 2018, Pooler et al., 2007; Selman et al., 2007).

Lee et al. (2017) found that nurses saw themselves as having more of a supporting role, perhaps in education and outreach and that there was fear and little interest by hospice staff in caring for people with dementia. The Davies, et al., (2013) study highlighted examples relevant to the historical context and development of hospices as organisations delivering regulated activity, the earlier era of hospice care being able to break the rules and thinking outside the box, compared to the later era of governance and parameters. This article also recognises the 'professional rivalries and jealousies' (Davis, et al., 2013 p.391) in relation to specialist and generalist services. This will be discussed further in the following section on workforce.

6.1.7 Workforce

Workforce skills and ability was the greatest barrier towards providing hospice care for people with dementia identified in the survey. Without delving into the qualitative data this would be very practical i.e. the need for training and education, funding to pay for additional staff with different skills and availability of staff in the local labour market. However, it was clear in the data the issue of workforce was far more complex, bringing in issues regarding role identity, a central institutional factor in this debate. The data below provides some insight into themes relating to the workforce:

Focus Group

'what I found very quickly is that when the word dementia is used that people feel very deskilled, very quickly, and when you ask people you know what would you have done differently if that patient hadn't got dementia, nine times out of ten the answer is well actually nothing, but having that confidence to do that erm seems to be an issue and I'm spending a lot of time reassuring people yes you're doing the right thing yes I would do the same etc' (FG F)

'I think er the nurse specialist teams probably, clinical nurse specialists I'm not certain that they really want to get involved' (FG M)

'.....you know they are the most difficult kind of group of people to look after if you like partly because of the environment but partly because you know behaviour that's, people could potentially be physically aggressive they're hallucinating they're frightened and they are telling you things that are really you know unusual they are the hardest people to look after usually the least trained staff are allocated to look after these people and I think whose gonna put their hand up and say let me be the one to look after that person if you really don't feel confident to do that'. (FG F)

Interviews

'I think it takes a quite a special person who've seen the light of the differences between cancer and dementia to be able to go into these [care home] settings and actually relate and not judge but relate to these people [care home staff].....I think you've just got to start small and remain focused rather than being overwhelmed by the number of care homes out there and the number of people with dementia' (I10)

'I think we've got to train interested people, you can't force people to get into dementia' (I10)

'dementia patients, the challenges are so different because they are still very able, they're not poorly their bodies are fully able they get up, they move around, they need stimulation, they need interaction, they need supervision, really they need help constantly through the day whereas a cancer patient you can go and see to the care and then you can walk away and leave them for six hours until you need to go back' (I6)

These workforce themes crossed over with the generalist v specialist debate, although there were more examples of this in the interviews as illustrated:

Focus Group

FG F -'I think it goes back to the kind of erm tsunami worry doesn't it so if you define yourself as a sort of specialist and you've got a boundary that then you know perhaps erm sometimes that's helpful and sometimes that's not helpful in terms of isolation' (FG F)

Interviews

'some of the older longer trained palliative care doctors I don't think they are like that I think they are much more supportive of nurses then you've got this kind of middle group that just seem to be resistant to any kind of change at all and it is almost like when they brought in the specialism it was like this holy grail that they had to fight to have this specialism and spent so much time defining what it actually meant rather than thinking about what the needs are and how we serve patients.' (I11)

'as a movement we need to get over ourselves that we're not this precious, ooh we're so wonderful because we deal with dying people, a lot of people deal with dying people as well so I think we've got to be bolder' (I1)

'I think doctors like MND because it's complicated' (I11)

The comments within the data suggests that the hospice movement is confused about its identity, there are those challenging the 'specialisation' and others embracing it. For some it is a means of rationing care and for others it's about professional identity. What was interesting in the analysis was workforce issues specifically around communication. This theme suggests that the difference in communication skills between people with cancer and people with dementia that may have an impact on someone's sense of self, their job satisfaction and how they make sense of their role i.e. how people make sense of themselves and their roles based on their interactions with patients:

'that's difficult for staff erm particularly for our community staff erm I think they erm they're used to a particular way of working which is a very, very, fulfilling way of working, it strokes their egos erm where they build a really close relationship with somebody and they do everything really, really well and erm obviously in an ideal world that's what we'd do with everyone, but the reality is we have to be much more pragmatic now about what we can afford to provide people' (111)

'I think it is capability, I think it's also preparedness and erm....I think there are lots of things that one might do when you look after people with dementia that's just not part of our culture so erm we're not used to restricting people's movements for example er we're not used to erm seemingly deceive people for example by putting medication in their food or stuff like that , people find that very very distressing in palliative care, people who are in mental health learn a different framework for autonomy and respect but our framework is very much based on high level of cognition'. (12)

'think the reciprocity issue is that the person with dementia can't say thank you, they've forgotten about you five minutes later and as a nurse I find that

incredibly difficult to care for people like that, I want them to know me, I want them to remember me and say thank you to me'. (I3)

This theme around the interaction between hospice nurses and their patients is potentially very significant. The significance is because identity, values, norms are important institutional concepts and may influence individuals in acts of institutional work and in their response to change. In the empirical search there was an article that was potentially uncovering a connection to this topic. Jones & Sambrook's (2010) research in four hospices, with a cohort of ten nurses (Section 3.1.4), found that they formed their psychological contract with their patients, not their organisation, which is what would be anticipated in most organisations. The potential connection is that based on this article and the comments above, perhaps the psychological contract is not with all patients but with those that they can communicate with. The psychological contract is with the patients that meet the practitioners need for job satisfaction and their sense of self, perhaps those with cancer and not dementia.

However, there is also a question raised in the comments whether the issues related to identity are factors of the hospice or the profession palliative care.

'I wonder if it's about the identity of the hospice or the identity of the profession because this whole thing about making palliative care a speciality, I think has....I can understand why people wanted to be attracted into the sector and not to feel as though it was putting somebody into a bed and mopping their brow, but on the other hand if you start talking about specialism then it's easy to fall into the trap of only wanting the interesting deaths.....frailty is actually pushing it one step further [than dementia].....I'm really clear in my, my personal values that erm everybody deserves a good death and no death should be deemed not interesting enough or not specialist enough for hospice care, palliative care, whatever you want to call it erm but there are a lot of different views out

there on that and especially in the profession, it's well, we know we will be looking after specific conditions where we can make a difference because there are medical things we can do and so forth and so you know if somebody's just died of old age, well you know, that's just life' (18)

Issues of identity also relate to the concept of legitimacy, i.e. one's sense of self or interpretation of an organisation might suggest what it is we perceive it is legitimate to be asked to do or not. The concept of legitimacy will be discussed next.

6.1.8 Legitimacy

There are several views to unpick these narratives related to workforce, identity and interaction. Chapter Two introduced the reader to the theoretical concept of legitimacy which is chosen as a relevant element of institutional theory that helps explain some of this narrative. Legitimacy is a concept relevant to organisational fields and described by Suchman, 1995 as

'a generalised perception or assumption that the actions of an entity are desirable, proper, or appropriate within some socially constructed system of norms, values, beliefs and definitions' (Suchman, 1995, p. 574).

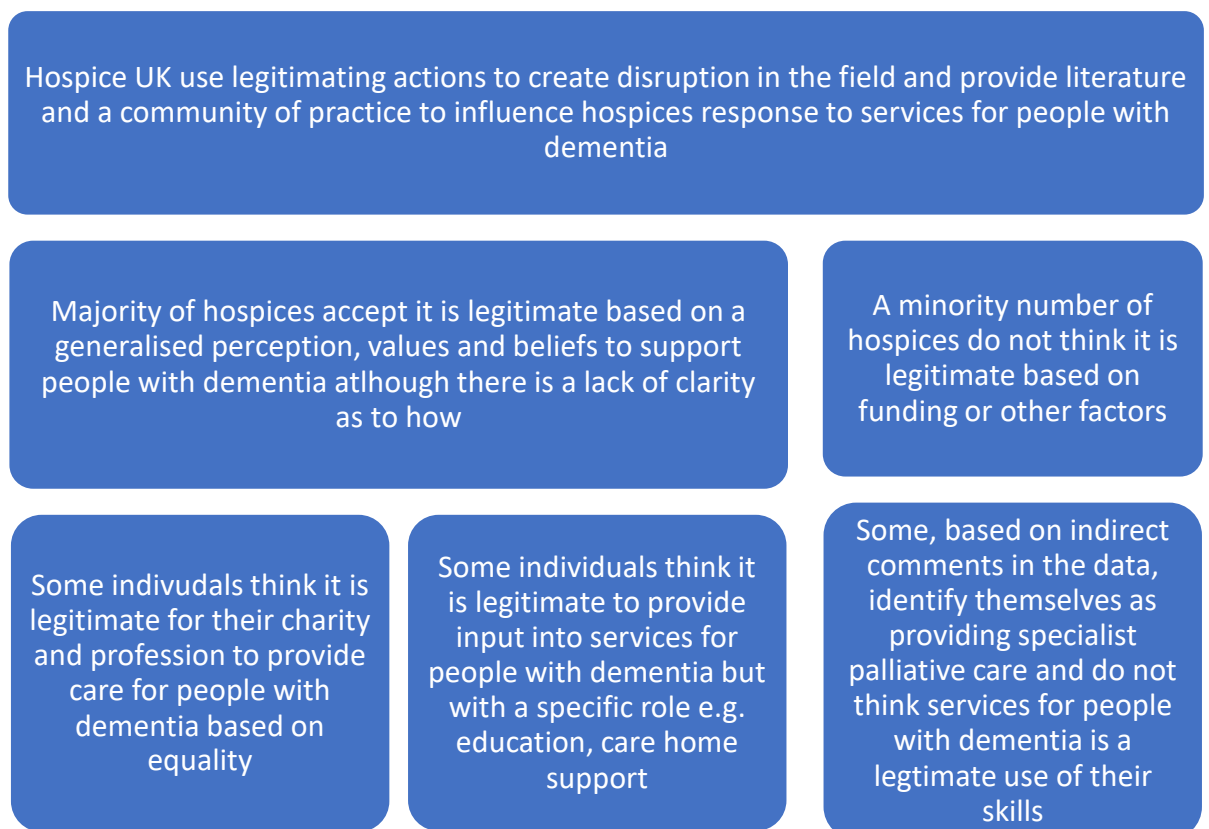
Legitimacy, like other institutional terms, creates a new language through which to explore the factors influencing hospices' response to services for people with dementia.

Based on the historical context of hospice, (described in Chapter Three) it has been accepted for over fifty years that it is legitimate for hospices to care for people with cancer. This is accepted by individual organisations, by the field, by Hospice UK, by the NHS, by the various professions, by the workforce and in some ways most importantly, by the local communities that generate millions of pounds for hospices every year. There has been work at the boundaries, however, this work does not appear to have the widespread legitimacy that cancer does and this creates challenges for the field in moving forward. The empirical literature in

Chapter Three describes some research in other areas such as haematology (McCaughan, et al., 2018) and heart failure (Pooler, et al., 2007, Selman, et al., 2007) that demonstrates how work at the boundaries has faced similar challenge in disrupting the insitutional norms of hospice care.

Legitimacy can influence and be a factor at multiple levels within the individual organisation and at field level and whilst there can be 'agreed' legitimacy, e.g. a strategy document and what is said at organisational or field level, there is also an individual view on legitimacy, described as the 'social evaluation' each of us make (Bitektine & Haack, 2015). For example, a model of legitimacy can be created in relation to dementia:-

Figure 6.1 – three levels of hospice legitimacy



The multi-level approach to legitimacy (movement, organisational and individual), described in figure 6.1 helps explain some of the field configuring actions evident by Hospice UK (conferences and 2015, publication) combined with variety of perspectives within the literature and within the fieldwork. Individuals have their

own views on what it is legitimate to be asked to do themselves, for their organisation to choose to do and for their profession. This is where both distinctive history and individual experience can undermine or reinforce views of legitimacy.

New institutional theory argues that members of an organisation will stay similar to other members, i.e. isomorphic behaviour. Remaining similar can stabilise an organisational field and the individual organisations within it as actions are 'legitimatised' e.g. become the assumptions, norms, beliefs and values that sustain organisations. There is, according to the data presented in this thesis, a recognition with the organisational field of hospices that the 'jolt' of dementia cannot be ignored. However, the lack of clarity relating to models of care and the mixed views as to whether the response is one of equality or one of a specific intervention means, that there is no single new 'legitimate' view. The only 'generalised assumption' in the data, is that doing nothing is not an option. There are no current and immediate threat of sanctions, for example, a reduction in statutory funding if hospices do not behave in a particular way, i.e. the data demonstrated that 67% of survey respondents are not being asked to provide services for people with dementia. Although content analysis for this question found that eight respondents felt that doing so was implicit or assumed. There is not a sense in the data, that hospices are concerned about voluntary income being reduced i.e. would the general public find it legitimate for hospices to care for people with dementia or would doing so change the beliefs, values and assumptions of local supporters?

The organisational field of hospice care is definitely aware of the 'jolt' but has no unified response. There are many practical challenges in supporting people with dementia which could be resolved. There is capability within the sector to create dementia appropriate, replicable models of care for different types of patients, it is relatively simple to provide training for staff or to blend the palliative / dementia workforce by recruiting new staff. Funding is a challenge, but redesigning services

can create capacity. All of that is possible. The lack of progress to date relating to services for people with dementia, this research is arguing, is due to institutionalisation and within that theory is the critical issue of legitimacy. There were comments for which legitimacy as an individual, organisation and field level could apply. For example this comment, is suggesting that it would not be legitimate for hospices to pick up the responsibility of caring for people with dementia:

'the hospice movement provides excellent palliative and end-of-life care at the moment to those to whom it can..... the can is important in that you're not going to compromise the sustainability and survivability of your charity just because someone says oh it's individual patients' human rights to have hospice care because they've got dementia, that opens up the road to ruin for the whole hospice movement'. (14)

This first quote uses the argument of sustainability to create the rationale of services for people with dementia not being legitimate. The following quote is also arguing, but from a different perspective, that of a hospice nurse, that it might not be legitimate. They did not choose dementia as their field of practice and it might conflict with their style of nursing:

'I think there's something too about people's attitudes towards dementia and actually when I think about my own nursing experience and what I felt I could and couldn't deal with, I knew end-of-life care would be for me during my training, which is an awful long time ago and erm but I knew I couldn't do things that might require much greater degrees of patience and er being, repeating things and that kind of thing and just wonder whether quite a lot of people in hospice nursing for example have a similar mind set, because if they didn't they might have gone into learning disability or maybe psychiatric nursing of being an RMN and things cause I'm not certain I could manage that kind of patience thing, so is there something in the mind-set perhaps philosophy that we're not even particularly aware of that puts us off caring for that kind of person keeps on repeating information and things so learning some of the things that we need to in order to be best as we can be at managing someone with dementia maybe conflict a little bit with our own particular nursing styles'. (FG F)

The next comment also focuses on the extent to which hospices could cope with a change of focus at an organisational level:

'there's a cynical part of me that believes hospices would struggle hugely with the untidiness of dementia and erm.. most hospices are not equipped to deal with mental illness, cognitive dysfunction...I think we have worked quite hard to keep mental illnesses out of hospices because it's difficult to manage, people can be crazy, they can be unpredictable er they can be demanding, they are often unhappy, they often do really dreadful things like trying to kill themselves, I mean not everybody at all, but that's the kind of association'. (I2)

On the other hand, there were comments suggesting that it is no longer legitimate to remain the same:

'I think it's going to make it more difficult for hospices to say no ... if you are really into equity and population needs and you know care for all, all these various strap lines that hospices have you know....the tide is just there now..... I wouldn't want to be the chief exec standing up saying we don't do dementia, I think it's a very difficult position to take'. (13)

6.1.9 The institutional nature of hospice care

This research is proposing that it is actually only hospice care for people with cancer that is truly institutionalised. That the history of the creation of the hospice movement, the social context in which it was formed, the specialisation which attracted oncologists into the field and possibly reinforced the narrative of cancer all contributed to the process of institutionalisation.

There have been developments within hospices but nothing has shifted cancer dominance for fifty years despite legitimating actions at various levels within the field and specifically by Hospice UK. The strong historical narrative explored in Chapter Three combined with professional and individual hospice identity, reinforced by the organisational field strengthens the suggestion that the movement is institutionalised. Therefore an understanding of organisational institutionalism as described in Chapter Two helps identify ways to explore and consider how the hospice movement might wish to consider an approach to change.

The application of organisational institutionalism theory in this research has highlighted three ways of considering an approach to change. The three options to improve end-of-life care for people with dementia are:

- Decoupling – this will be discussed next in this section
- Deinstitutionalisation followed by reinstitutionalisation – this will be discussed in Chapter Seven
- The emergence of a new social movement

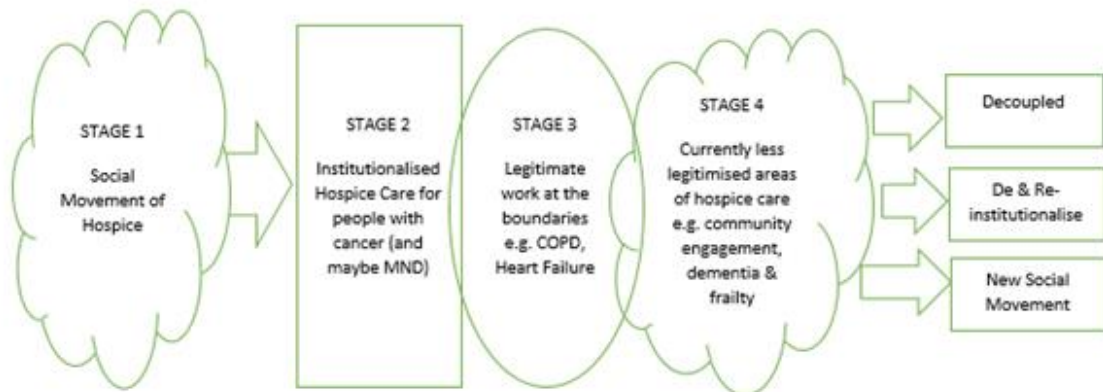
6.1.10 Decoupling

This is an institutional concept that enables an organisation to get involved in possibly less legitimate activities by keeping it removed from core activities (George, et al., 2006). Decoupling is less risky than 'breaking out of the iron cage' and reduces the internal and external risks associated with institutional change (George, et al., 2006; Hirsch and Bermiss, 2009; Meyer and Rowan, 1991; Hodges and Read, 2018). New external partnerships can be an example of decoupling. For example, there is a particular hospice that works with another charity and clinical commissioning group to provide a dementia service in care homes. This award-winning service has not however, disrupted the core clinical service delivery across the hospice because it is decoupled. It could be argued that 'decoupling' is a coward's way out, it does not address the root cause of institutionalised behaviour, that depends on the view as to whether staying the same might threaten sustainability and therefore the change is essential. However, if a decoupling strategy meets a need, perhaps it is a pragmatic way forward that might lead to reinstitutionalisation over time.

An institutional model

A model is proposed (figure 6.2), by Hodges and Read (2018) which describes the researchers' view of the institutionalised nature of the hospice movement.

Figure 6.2 - The evolution and current structure of hospice as an institution
(Hodges and Read, 2018)



The model describes the three options of institutional change based on the current status of the field. It recognises in Stage 1 that hospice care originated from a social movement. It then proposes that it is only cancer care that is truly institutionalised. There is a suggestion that MND also might be, it was a condition that Dame Cicely Saunders supported at St Christopher's (Boulay, 2007) as indicated in Stage 2. However, this may not have been universal across all hospices. It then acknowledges in Stage 3 that there is legitimate work happening at the boundaries, in particular heart failure where there are examples of service provision (Wilderspin et al., 2017). This area of service provision is less contested in the field than dementia. Stage 4 highlights work that is less legitimate although this might vary in some individual organisations and certainly the work by hospices categorised as 'community engagement' is arguably moving towards stage three. There are national groups working together and a sense that this work addresses some practical issues of reaching more people who could benefit from hospice care. The model highlights dementia and frailty as 'less legitimate'. If dementia is contentious, it is at least recognised as a palliative condition and the survey data suggests a willingness to engage, frailty is further away from being recognised as a legitimate area of engagement by hospices. The model is not meant to be one-directional, it is possible

theoretically, whilst not evidenced in practice, that other areas of work could become institutionalised.

Activities in Stage 4 can move to Stage 3, but it has not yet been proven that anything can move to stage two. For dementia, either the solutions are via decoupled activities, a new social movement emerging and in essence taking away the problem of dementia from hospices, however, as Hodges and Read (2018) articulate, that could impact on the relevance and ongoing legitimacy of the field of hospice care. The other option of deinstitutionalisation followed by reinstitutionalisation is about institutional change and this will be explored in Chapter Seven.

Chapter summary

This chapter has considered the data at field level and explored the relevance of organisational institutionalism in addressing the research topic. The chapter has considered the role of Hospice UK as a meta-organisation and considered the extent to which participants in the fieldwork felt Hospice UK had a role in influencing the direction of hospice care. The data has demonstrated the desire by the hospice movement to address the challenge of hospice care for people with dementia but has also provided evidence of the many challenges that this presents, not just the practical challenges highlighted by the survey e.g. workforce skills and ability, finance and existing demand but also institutional factors such as historical context, assumptions, beliefs, identity and legitimacy. The data highlighted concerns within the hospice workforce that are symbolic, i.e. how professionals make sense of themselves through the types of patients they care for.

The extent to which the field is institutionalised needs to be considered in the language and methods used to create change, if that is indeed what the field wants to achieve. This chapter has introduced concepts such as legitimacy to help articulate some barriers to change based on what is perceived as legitimate.

It has also introduced a new model produced from this research. Chapter Seven will look at the fieldwork through the lens of institutional work theory introduced in Chapter Two. In addition, Chapter Seven will consider a model of institutional change by Greenwood et al. (2002) and how useful it might be for the hospice movement.

Reflection

Data, data everywhere! It has been a challenge trying to pull together so much data alongside so much theory and present it in a way that feels logical.

Breaking up the analysis chapters into two has helped do this. Occasionally, I've wondered whether addressing the research topic from purely an individual agency level OR a field level would have been easier and still appropriate for a doctorate. However, one makes little sense without the other and therefore I hope the challenge of considering both angles is more useful to practitioners considering issues of institutional change.

The model produced based on the theory that is presented and discussed in Chapter Six was really exciting to develop. I started to draw it on various scraps of paper as I was discussing elements of my own hospice's strategic development and perhaps why there were some cultural challenges associated with change. The people who saw me draw and explain it seemed to resonate with what it was suggesting. As the model took shape, and my confidence in the theory grew, I was able to write an article around it (Hodges and Read, 2018), and then discuss it during discussions I was invited to in both Australia and New Zealand. That feeling of developing thinking within our own minds, then sharing it tentatively at first, hearing that it makes sense to others publishing it and then presenting it more confidently, has been a highlight of this whole process.

7 Chapter Seven – organisational institutionalism; institutional work and change

Chapter Six considered the fieldwork from an organisational field level, utilising institutional concepts such as legitimacy and proposing, from the data, a model of hospice institutionalism. This chapter will now consider the use of agency in relation to hospice care for people with dementia. It is split into two sections; institutional work as a key theoretical lens in this study and then the second section exploring institutional change.

7.1 Section one: institutional work – agency in maintaining or disrupting hospice care.

The theory of institutional work was introduced in Chapter Two, it is 'the purposive action of individuals and organisations aimed at creating, maintaining and disrupting institutions' (Lawrence and Suddaby, 2006 p15). In simple terms, acts can undermine or reinforce rules and compliance or certain behaviours and beliefs by providing negative or positive examples (Lawrence and Suddaby, 2006; Fredriksson, 2014). For example, if referral criteria was amended and someone with dementia was more likely to be accepted into hospice care, and this new rule was audited for compliance it would be an example of a rules based approach to institutional work. Or perhaps if examples of stories that were positive or negative around the care of someone with dementia were being used formally or informally that might maintain or reinforce certain beliefs and assumptions.

This next section will present evidence of institutional work

7.1.1 Evidence of disrupting acts of institutional work

There is evidence of institutional work within the data, which are discussed in Chapter Seven. It became apparent that acts that would be classed as 'maintaining' the norms of hospice care (Lawrence and Suddaby, 2006) are

disruptive in achieving the future vision. Therefore, depending on whether someone sees an act as maintaining or disruptive would depend on an individual's perspective e.g. one CEO who was very clear in their vision of their hospice as having equal access commented that:

'leaders whatever that means, the people who are in charge of hospices who are just sitting on their laurels not thinking about dementia, not thinking about how they meet the needs of older people erm, they, I don't think they are prepared to challenge the medical establishment and I think; I don't think the medical establishment do it because they're prejudiced to old people I think they do it because young people fulfil a need and because they're more interesting' (I11)

Their view was that the people who are not advocating change and acceptance of services to people with dementia, whilst they may be involved in acts of 'maintenance', are in fact disrupting the CEO's ability to achieve their vision. The CEO in enacting their vision of equal access is 'attacking the legitimacy or taken-for-grantedness of an institution' (Lawrence, et al., 2009, p. 48).

In the context of the theory, the concept is clear that maintaining acts are about continuing with the institutional norms and narrative with acts of disruption being those in favour of change (Lawrence and Suddaby, 2006). There were many examples of acts disrupting the norms of hospices not routinely providing services for people with dementia. Many of these are 'acts' of institutional entrepreneurship. The Hospice UK dementia community of practice allows these institutional entrepreneurs from individual organisations to join together to share, learn and possibly galvanise each other. 'New institutions arise when organised actors with sufficient resources (*institutional entrepreneurs*) see in them an opportunity to realise interests they value highly' (Di Maggio cited by Lawrence, et al., 2009 p 37). In the survey 26.8% (n = 22) of responses to the question 'in considering your response to hospice care for people with dementia has this

started with...’, related to an individual with a specific interest. This is consistent with some comments from the interviews and focus groups for example;

‘we had one girl who had a special interest as a RGN working there and she got...she’s done so much and I think it’s the domino effect now we’re here you know ideas come and passion comes and people get enthused don’t they hopefully erm so it’s kind of, we just need to start the ball rolling’ (FG F)

‘We’ve got an amazing healthcare assistant on one of our sites who has come from a specialist dementia unit and she is bringing so many skills with her, practical skills for her colleagues to use and she is an absolute inspiration’ (I5)

‘I know some of the hospices that have developed services quite actively it’s often been led by one local champion whether that’s been a nurse or a doctor or an executive’ (I9)

It should be acknowledged that for individuals to be able undertake disruptive acts of institutional work the environment must be conducive to this. If an institution is indeed an ‘iron cage’ (Zietsma & McKnight, 2009, p. 143), these individuals would surely be sanctioned for not complying with the institutional norms. The CEO may well endorse these actions, although possibly not the Board of Trustees. These comments show how despite an environment accepting of institutional entrepreneurship relating to services for people with dementia, this may not be shared throughout the organisation.

‘I don’t think it’s something I need permission from the trustees to do because we’re here to serve people with terminal illness in.....and dementia is one of those illnesses’ (I11)

‘so many times, there is a complete division and I would say that the Boards are maybe 10 years behind the exec team and the

exec team are, in many cases, just going off and doing it and managing the board and making sure they don't stop them'. (18)

'err... no, I think the executive team are usually the most up to date in terms of policy and what others are doing and their data, the Trustees often and certainly in the experience of my own hospice didn't see dementia as something that hospices should get engaged with at all' (19)

Resistance to change can be at different levels in the organisation and possibly with specific groups of staff as different beliefs of what a new institutional norm should be varies. There was other evidence of tension between acts of disruption and the need for others to maintain the institutional norms, for examples:

'Sometimes when you see a moral imperative of, you know, there's people out there who are in pain in care homes, it's that passion to say we are going in, sod it we're going in, we know there's people there with pain, we know there's people who need help' (13)

'Leaders whatever that means the people who are in charge of hospices who are just sitting on their laurels not thinking about dementia, not thinking about how they meet the needs of older people erm, they, I don't think they are prepared to challenge the medical establishment and I think I don't think the medical establishment do it because they're prejudiced to old people I think they do it because young people fulfil a need and because they're more interesting (111)

'I've hadcome to me really cross because they've said you keep talking about dementia and of course we want to help people with dementia but if we open up our doors to people with dementia we'll be flooded and we can't do that so we're going to be overwhelmed, we're going to go out of business and, so please stop talking about dementia it's just too complicated for us' (18)

Evidence of maintaining acts of institutional work

There are different ways that acts of maintenance can take shape, for example, when questioning in the field work, how decisions were made relating to services for people with dementia, one respondent appeared to have avoided a wider organisational debate (an act of institutional work, maintaining the status quo);

'well frankly we've been so busy with everything else and not including dementia' (14)

Other parts of the system can also undertake acts of 'maintenance' demonstrating that not all acts of maintenance are from inside the institution;

'So it was quite hard even though we were saying well look at your service is a 9 to 5 service and it's really threadbare and if we work more closely together we can provide the out of hours care and all of the rest of it he, he [psychiatrist] wasn't to be persuaded about partnership working so the opportunity to shift that really came when he moved on and we got another psychiatrist involved in that service to have a formal arrangement with them' (111)

Internal systems can also be 'acts' of maintenance. Referrals to hospice care generally come from outside the organisation with internal systems determining who is then accepted for hospice care.

'So it's okay being the prophet and saying evidence says this and we know we've got to do this, if we don't reach the hearts of our staff and our colleagues we will find ways to sabotage..... I know hospices up to last year, were finding ways to not admit people with dementia' (I3)

In the survey when commenting on the question 'Does your hospice provide care for people with a primary or secondary diagnosis of dementia?' 4 of the 16 respondents to free text questions, (25%) commented on the need for referral processes to be amended. In the survey comment below, a change was made to internal systems. However, the second and third comments are more typical in the data i.e. preconceptions of hospices, people's beliefs regarding the institution of hospice and not associating it with dementia.

'technically yes but we don't have a specific 'dementia service' - we respond to the specific needs that are identified in the referral. We had found that people with dementia as a primary diagnosis were not getting through our triage system and yet were dying quite quickly after referral and so we instigated a change to practice so that all referrals of people with dementia as a primary diagnosis are visited by a CNS to ascertain their needs and how we might best support them.' (S2)

'It is very rare that a patient with primary dementia is referred. Secondary is slightly more common. I cannot recall a referral into the community services or day therapies with dementia.' (S9)

'there's something about the education or the message we give as hospices for our referral criteria, people that can so you know, in Gold Standards Framework (GSF) meetings that we go to, how often are people with dementia discussed in those lists, not often in our area erm so yes there's education about... you can refer patients to us' (FG F)

It is not possible to know whether in the first example the change to the referral process was an act of institutional work, it may well have been. However, the referral process allows for acts of both disruption and maintenance – e.g. the changing of the process to legitimise the acceptance of a patient different to those traditionally accepted or an individual choosing to take a patient who does not meet the referral criteria to either disrupt or maintain institutional norms.

Section 7.1.1 provides evidence of acts attempting to disrupt the nature of hospice care to include people with dementia and also acts endeavouring to maintain the status quo. The call for change, from the fieldwork, is predominately coming from a moral drive to meet the needs of the local community or to address deficits in care. The almost unanimous response in the survey agreeing that hospices have a role to play, is despite the lack of finances, workforce capability and service capacity. There isn't evidence in either the focus groups or interviews that suggests providing services for people with dementia is seen as a commercial opportunity, the reality of the financial challenge is addressed by some research participants.

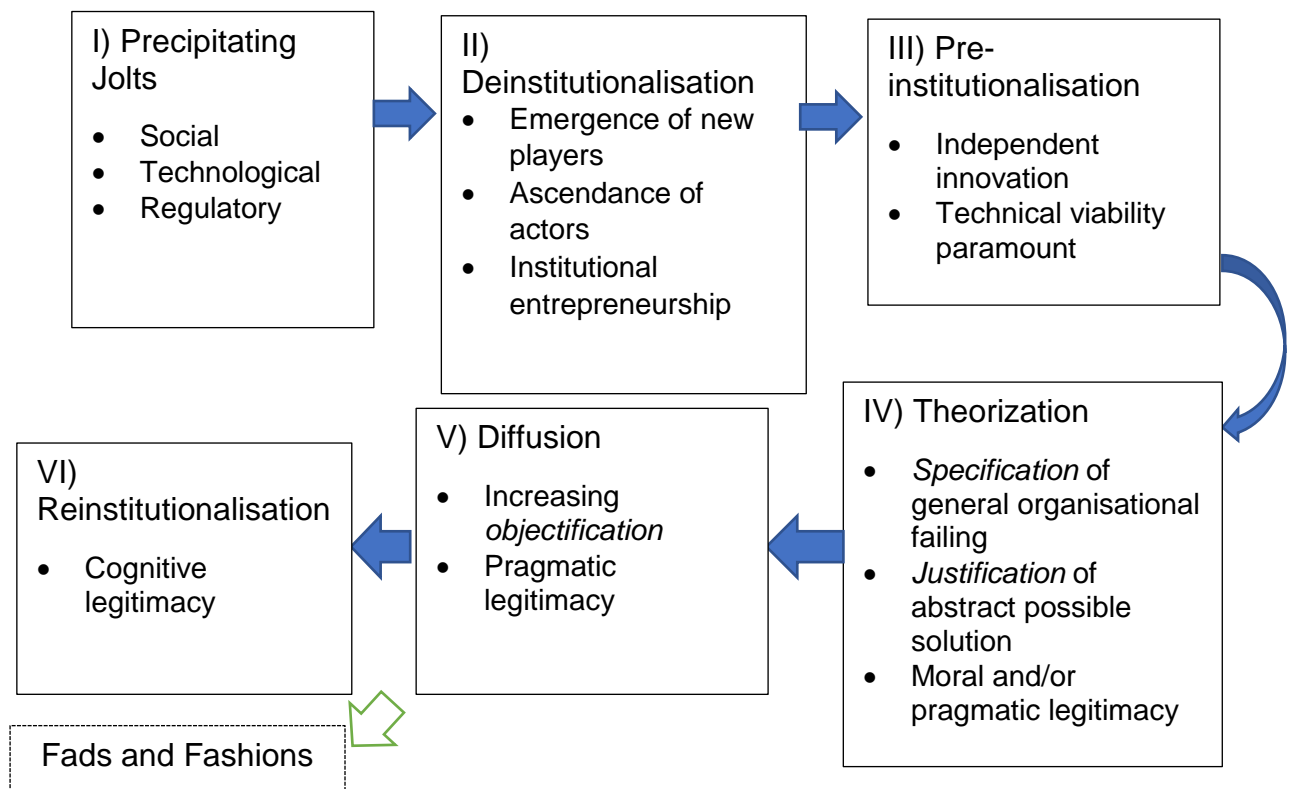
There are suggestions within the data that some acts of institutional work aimed at maintaining hospice care relates to issues of professionalization, the suggestion that some professional groups are more or less opposed to services for people with dementia.

In summary, exploring acts of institutional work within the data collected, provides insight into the challenges within the field towards change. Being able to consider institutional work themes enables further exploration to take place to consider how to address any resistance to change. Resistance to change in an institutional sense, can be far more related to beliefs and values than purely systems and processes (although these can be methods of disruption or maintenance).

7.2 Section two: institutional change

This final section will aim to pull together the insights from the data analysis by introducing and exploring a model of institutional change by Greenwood et al. (2002), the article in which this model was introduced was based on the professional services sector and therefore a different context. However, based on the data and insider knowledge it perhaps explains why hospices have failed to change.

Figure 7.1 – Stages of institutional change (Greenwood et al., 2002 p60)



Precipitating Jolt

Greenwood et al.'s model (2002) starts with a 'precipitating jolt' i.e. one that is perhaps unexpected or undesirable. In the case of hospice care for people with dementia Chapter Three provided evidence of the sociological jolt of dementia. Whilst the demographic changes and the growing prevalence of dementia was well documented, the potential impact on the field of hospice care, or the requirement for a response from within the field was slower to be acknowledged, i.e. the gap between NCPC Reports 2006-2009 and the Hospice Enabled Dementia Care publication in 2015 (Hospice UK, 2015). It is acknowledged some hospices have been providing care for people with dementia, however, this hadn't spread across the hospice movement.

Deinstitutionalisation

The phase of deinstitutionalisation happens as actions take place to break out of the 'iron cage', this may well be via disruptive acts of institutional work, challenging normative assumptions and values or amending rules and systems. Examples of this within the data were employees demonstrating institutional entrepreneurship by championing change in their organisation:

'I mean I've worked at the hospice for just over 10 years but since er XXXX come on board with her 30 years of dementia nursing and her mental health background I've just learnt in the last 6 months a phenomenal amount about how to care for someone with dementia and vice versa that she's learnt a lot form us about end-of-life' (FG 5)

Nationally disruption can take place via 'field configuring events' (e.g. publications, conferences, grant funding). Disruption may also involve new actors joining the field, e.g. Admiral Nurses part funded by Dementia UK and part by an individual hospice.

'I'm a new Admiral Nurse into post so I've only been into post since April this year and my background is RMN and I have joined a community palliative care team a very large team 28 palliative care nurses and I'm also providing support to day therapies, the inpatient unit etc and what I found very quickly is that when the word dementia is used that people feel very deskilled very quickly and when you ask people you know what would you have done differently if that patient hadn't got dementia nine times out of ten the answer is well actually nothing, but having that confidence to do that erm seems to be an issue and I'm spending a lot of time reassuring people yes you're doing the right thing, yes I would do the same etc' (FG F)

There were many examples of acts of institutional work aiming to disrupt the status quo of hospice care (Section 7.1.1) however, the data hasn't shifted and there are also many acts of institutional work or comments around role/professional identity that demonstrate that hospice care for people with dementia has not yet been universally accepted as legitimate. Some individual hospices may have moved beyond the deinstitutionalisation phase, however, this has not been achieved at field level. Therefore, the remaining stages of Greenwood et al.'s (2002) model, have not yet been achieved for dementia and, based on Hodges and Read's (2018) model (Figure 6.2, page 188) have not been fully realised for anything other than cancer. This is not ignoring the wide range of services to which hospices contribute but based on a full shift of narrative that creates the climate for institutional change where new norms are created and accepted.

Pre institutionalisation

This stage includes independent innovation and articulates that technical viability is paramount. There are examples in the data of 'independent innovation' such as new services, projects, pilots and partnerships at individual organisational level for example:

'She is phenomenal in terms of the impact so she, she's we have some money from XXXXX so she's been for 2 and a half days a week to specifically focus on dementia and what she's been doing is working alongside the XXXX dementia service going to their team meetings case finding essentially with them erm taking referral directly from them but also from others now erm doing joint visiting referring people back to them that they didn't know about that's the other it's not just in it's out as well and erm a lot of support for carers really the referral on to other hospice services has been quite significant' (I11)

Hospice UK have showcased some of the work in relation to dementia via publications and conferences (Hospice UK, 2015), adding legitimacy to the expansion into the needs of this demographic. Technical viability not only relates to the model of care which is confused, (Section 6.1.6) but also from a financial and business model perspective. This stage appears to be missing in the movement in relation to dementia. There were fewer comments in all of the data relating to the economic impact of widening access, however, it was a strong theme in the survey. Balancing widening access whilst ensuring business sustainability is a challenge. In the data there are two polarised comments:

'my argument would be well perhaps we've seen too many people with cancer you know if we have to limit our resources it's about changing the model of care across the board it's not just about having just a slightly different model for dementia it's about saying ooh what are we doing for somebody with a cancer diagnosis who is actually quite stable' (I11)

' we need to have some reality and some common sense creeping in to the debate er and the reality and the common sense is hospice movement provides excellent palliative and end-of-life care at the moment to those to whom it can and does cater, the can is important in that you're not going to compromise the sustainability and survivability of your charity just because somebody says oh it's individual patients human right to have hospice care because they've got dementia that opens up the road to ruin for the whole hospice movement' (14)

These comments illustrate well the tension of widening access versus financial resources and clarity of clinical models i.e. the technical viability of change.

Theorization

Stage four moves on to 'theorization' and a critical stage in institutional change and one that is intrinsically linked with legitimacy (Greenwood et al., 2002). In hospice care at field level, this stage has never been completed, although there are perhaps again pockets where elements have been started or partially completed. It is very difficult to theorise 'general organisational failing', when 54% (n = 45) of hospices are concerned about existing demand for services, there is high satisfaction in the provision of care (Centre for Health Services Studies, 2013) and c. £2.7m million is raised via voluntary support daily (Hospice UK, 2016). If there is an agreed failing within the field then local innovations and solutions from stage 3 (pre-institutionalisation) can be proposed as a way forward. Whilst there may be a perspective that the hospice movement may be failing to meet the needs of people with dementia, this hasn't been accepted as legitimate practice across the movement, i.e. is it a failing or is it a new demographic? The comments in the data are incredibly varied and emphasise the lack of a consistent view from research participants within the field, the selection of comments below are to demonstrate this variety of opinion which reinforce the argument of a lack of theorization:

'I was very challenged by alternative voices about hospice and hospice care and I would say that that was partly from the public er we did a public event that was eye opening very uncomfortable I have to say and erm I remember going to visit politicians and taking evidence from people outside the sector who really erm thought that our lack of attention to people who traditionally hadn't used hospice care was part of our downfall' (12)

'if you think about hospice care when Dame Cicely set it up originally it was for cancer, well we've all virtually all of us have moved way beyond just cancer erm so why not into dementia too well the answer comes to sheer scale er and the ... as I was saying earlier I really do not believe that the finance is available to expand the hospice movement to take on dementia care across the nation' (14)

'I still don't think hospices are particularly good at articulating what they've been doing for the last 50 – 60 years let alone taking on dementia and other things and er we just need to be much more in people's faces and think about what we are doing in order to make sure we garner the appropriate amounts of support and understanding, get the right kind of levels of expectation service and things' (FG M)

Greenwood et al. (2002) articulate that theorisation is how localised practice that varies from the traditional norms become replicable by other organisations within the field and becomes accepted as a solution to the 'problem' that the organisations at local and field level is failing to solve. The different view on models of care mean that localised practice is not becoming replicable at pace or scale at the time of this research.

Greenwood et al.'s (2002) study of the professional business services field in Canada started with an opportunity rather than a problem. The extent to which dementia is a problem or an opportunity is unclear. Their study summarised that the lack of 'a convincing problem probably influenced the indifference to the idea' (Greenwood et al., 2002 p.72). Traction was achieved when the opportunity was

re-framed as a problem and change was presented as 'natural, almost inevitable, progression. Change is progressive. Change is normal, whereas reluctance to change is unusual' (Greenwood et al., 2002 p72). In addition language was used to create an increased impetus for change and to 'invoke professional values' (Greenwood et al., 2002 p72). However, it took twenty years for the change to be accepted.

The Greenwood et al. (2002) study provides useful insight into the stages of institutional change, despite being a different field. The suggestion is that without theorisation, institutional change cannot be achieved. An area of interest for a future study would be to utilise 'discourse analysis' which is a study of written text, (Gomm, 2004) to determine how 'theorisation' has been attempted. The quotes which follow are from the opening pages of Hospice Enabled Dementia Care (Hospice UK) and demonstrate the use of more emotive language, calling for action from the hospice movement:

'Notably there is now also overwhelming evidence of a need to redress the poor care towards the end-of-life people with dementia experience because of their diagnosis' (Hospice UK, 2015 p3).

'The document argues convincingly that hospices should build skills and relationships so they can offer 'hospice enabled dementia care'... We, at Hospice UK, believe this is a journey hospices must consider and through which they could make a real difference' (Hospice UK, 2015 p3).

'It is crucial hospices find a role and position within this challenge. How individual hospices respond will differ according to local need ... It is no longer an option for hospices to say 'we don't do dementia' (Hospice UK, 2015 p8).

'We need to find our place outside hospice walls in dementia care, so we can contribute to the huge social problem. We cannot wait for people to come knocking on our doors; we must go more than half-way to engage with others. We need to be excited to find our place. But have we, as 21st century hospices, got the organisational culture, drive, confidence and humility to partner, educate, influence and disseminate good care? (Hospice UK, 2015 p11).

Hospice Enabled Dementia Care (Hospice UK, 2015) attempted to articulate the problem and provide possible solutions, including local examples that could be replicated. The survey results show that 32% (n = 26) of hospices used the publication when considering their response to services for people with dementia. The document provides different ways that hospices can engage with dementia, suggesting that it isn't 'one model fits all' but that everyone should do something. The concern around models of care (Section 6.1.6), may suggest that the problem is being seen through an institutional lens i.e. applying existing norms to a new cohort of people, rather than a fresh approach. For theorization to succeed the earlier phase of pre-institutionalisation needs to have been successful i.e. 'technical viability'. The Hospice UK report whilst demonstrating the variety of ways hospice can engage, it is silent on issues relating to finance. There are no costed examples for hospices to seek assurance from, therefore, undermining technical viability as a precursor to theorization.

Diffusion

The stage after theorization is stage 5, diffusion; Greenwood et al. (2002) cite Strang and Meyer in that 'models must transition from a theoretical formulation to social movement to institutional imperative' (Greenwood et al., 2002 p 60). This

quote would apply to institutional change in fields such as hospice care given its history. The strategy to be achieved in this transition is 'nesting and aligning new ideas within prevailing normative prescriptions, thus giving them moral legitimacy' (Greenwood et al., 2002 p60).

The data does not yet suggest that diffusion is happening across the movement, although there appears to be perhaps the acceptance of a moral legitimacy i.e. the survey results stating that 99% (n = 81) of hospice felt that there was a role. The earlier stages of pre-institutionalisation and theorization having not been completed, would, based on Greenwood et al.'s (2002) model, impact on the success of diffusion.

Re-institutionalisation

There is little to contribute from the data on this stage of Greenwood et al.'s model. It is the closing of the loop where transformation is complete and new norms are embedded. There may be a handful of hospices who individually are moving towards this and may achieve it in time. Of those interviewed, there is a long way to go, some sites had services that are 'decoupled' or focused on environmental change and becoming dementia friendly. There were one or two examples of an institutional entrepreneur infiltrating the existing culture which may over time create sufficient change. However, at field level, there is no evidence from the research to support re-institutionalisation being anywhere near achieved assuming it is even desirable. Given Greenwood et al.'s (2002) study demonstrates the process in the professional association's field took twenty years, hospices are at the beginning of that journey, however, the demographics would suggest there isn't twenty years to make a difference.

Chapter summary

Greenwood et al.'s (2002) model of institutional change provides a framework by which hospices can individually and collectively consider their organisational position aligned in relation to change. Comparing the fieldwork data against the model helps create an evidence based narrative regarding which stage the

hospice movement is currently positioned when it comes to services for people with dementia. The study that Greenwood et al. (2002) conducted, provides descriptions of each of the stages that helps consider what hospices would need to do to achieve institutional change. The data compared against the model suggests that the hospice movement has not yet achieved Stage 3 – pre-institutionalisation, in particular around demonstrating a technically viable solution from a service, finance and workforce perspective. Using a model also presents an argument around the lack of an organisational failing possibly being a block to the change process based on Greenwood et al's (2002) model. Hospices are perceived as successful organisations on a variety of factors, including voluntary support, numbers of volunteers and patient and family satisfaction. If the organisations are not 'failing', the impetus for change is harder to achieve. The Greenwood et al. (2002) study observed that the use of language was key seeing a shift in the field and that the change was achieved over a twenty-year timeframe. The literature in Chapter Three, presents a chronology from 2007 to 2017 highlighting the increasing narrative of a need to address end-of-life care for people with dementia and growing question regarding the input from hospices. This links with the argument that the hospice movement is 'stuck' around stage 3 and 4 of Greenwood et al.'s model.

The next and final chapter will bring together conclusions from this thesis; what knowledge the study has added; recommendations for future practice; and areas of future research.

Reflection

I've really enjoyed learning about institutional work and the types of acts that can disrupt or maintain an institution; it was satisfying seeing examples of this within the data. The data was collected in parallel to much of the reading on institutional theory, although the literature review was an iterative process

throughout. Therefore there were no specific questions that would lead to being provided examples of institutional work. They just exist.

Discovering the Greenwood et al. (2002) model was a seminal moment in my research journey. As an insider researcher, you cannot ignore your existing knowledge, whilst Greenwood et al.'s (2002) article was for a different sector the parallels to me were obvious. It was also fairly obvious as to which stages of the model the hospice movement appears to do well and where it gets stuck when it comes to change. I have had to make sure I've not kept the model without challenging its relevance i.e. ensuring that the model doesn't drive the analysis but that the data is paramount. Sharing the Greenwood et al. (2002) article and model with colleagues and discussing my preliminary research findings in the context of the model confirmed it provides a structure and a language that was useful when exploring change within the hospice movement. I plan to do more with the data in relation to Institutional Work Theory for a future article.

8 Chapter Eight – Conclusions

In concluding this thesis it is first important to ensure that the research questions have been addressed. Therefore, this first section will discuss each question and where relevant cross reference to sections of this thesis. Following this structured approach there will be a broader discussion to bring this thesis to a conclusion including recommendations for practice and for further research.

8.1 Addressing research question 1

This section will address the question:

To what extent does the history, culture and identity of the hospice movement support or inhibit responses by hospices to the press (in policy, demographic changes and public expectation) of development services for people with dementia?

This section will be structured to address each of the sub-questions related to this key question:

How are hospices defined?

There are multiple ways of defining hospices, one of the first areas of contention is in expressing their organisational form as an institution, and this is discussed in Section 1.2 and within Chapter Two. Defining hospices as an institution needs to be re-framed to engage with the theories discussed in this thesis and avoid the connection with institutionalised care.

Hospices can be defined in two ways, functionally and symbolically. In terms of a functional definition, Chapter One section 1.6 discusses the various definitions that apply to hospices from a service perspective e.g. end-of-life care and in particular generalist and specialist categories of palliative care. The definitions, depending on how they are used, can relate to capability, practice, strategy, identity and therefore a key to stakeholder understanding and engagement in change. Chapter Three Sections 3.3, 3.4 and 3.5 argue 'definitions' are a key consideration within

this research i.e. do people with dementia need specialist or generalist palliative care. Interview participant four considered 'hospice' as a *'philosophy of care'*. In the context of this thesis hospice, from a functional perspective, hospice is defined as 'care provided by hospice organisations' (see Chapter One, Section 1.6)

From a symbolic perspective, Chapter Two considers the issues of identity and culture as aspects of institutional theory. Selznick (1957) recognises the history of an institution and how that contributes to identity and how people define an entity such as a hospice. Both social movement theory and institutional theory recognise the importance of symbols, narrative and cognitive understanding. Hospices have these in abundance (for example marketing and public relations raising awareness and funds via stories in traditional and social media) and therefore how a definition is socially constructed will depend on the perspective and interpretation of the individual or group being asked and how they make sense of themselves. This complexity surrounding the understanding of the definition of hospices is a central theme within this thesis.

How is the 'field' of hospice care (hospices collectively) defined and organised?

Section 1.2, Figure 1.1 (page 9), Sections 2.1, 2.2.2, 2.3 and Chapter Three, Section 3.2.7 critically describe what an 'organisational field' is theoretically and how the field of hospice care is organised. Also described within these sections is how hospices collectively meet the criteria of Powell and DiMaggio's (1991) definition of an organisational field which is important if elements of theory are to be applied, i.e. field level analysis. Section 2.3, describes the role of Hospice UK as a meta-organisation its relationship within the field including some of its challenges. There are a range of field level organising factors that can directly influence the topic of dementia e.g. the community of practice, conference presentations, and articles published in the e-hospice journal. These can be described as field configuring events (Section 3.4.1). There are other indirect

organising influencers within the field such as clinical leadership forums, regional meetings, chief executive forums where issues impacting the field can be constructively discussed.

Understanding the field is important in understanding how change can be supported or impeded.

How are hospices, individually and as a 'field' reading and responding to internal and external pressures to develop services for people with dementia?

The pressure to develop services for people with dementia is currently coming from external sources but predominately from within the hospice movement. The external impetus for change identified within the fieldwork is not coming from legitimising organisations that could impose sanctions e.g. clinical commissioning groups. 83% (n = 67) of survey participants were not being asked by NHS funders to provide services for people with dementia. The other external pressures are mainly in the form of reports from organisations such as Marie Curie along with the Alzheimer's Society (2014), Department of Health and Social Care (2015) and National Institute of Clinical Excellence (2006). These reports advocate improvements in the access of palliative care for people with dementia, for example, stating that 'less than 1% of people in hospices in Europe had a primary diagnosis of dementia' (Marie Curie, Alzheimer's Society, 2014, p. 9). However, as these organisations cannot directly influence the strategic decisions of hospices, any influence at this stage must be indirect and these reports might contribute to a general narrative which could create an internal shift.

Within the movement the internal pressures are at field and individual hospice level. Hospice UK have supported a Dementia Community of Practice and also published a guide Hospice Enabled Dementia Care (2015), the role of hospice UK is discussed in the following section. However, in the context of this question and how the field is reading and responding to the pressures, Hospice UK's

dementia report was pivotal (Hospice UK, 2015). 32% (n = 26) respondents in the survey said they had utilised the report as part of their consideration of a response to developing services for people with dementia. The language in the report was compelling and emotive, 'overwhelming evidence of a need to redress poor care' 'we, at Hospice UK, believe this is a journey hospices must consider and through which they could make a real difference' (Hospice UK, 2015 p. 3) and the suggestion of a human rights imperative. In reading the need to respond, the report provides practical examples for hospices to consider. Considered against Greenwood et al.'s (2002) model of institutional change, perhaps the technical viability in relation to finance was missing and momentum not maintained.

At an individual hospice level, there are examples of acts of institutional work by employees, some focus on maintaining the status quo and other are acts of disruption demonstrating the lack of a cohesive and embedded strategy and approach to dementia. There are examples of institutional entrepreneurship with individuals championing change via acts of institutional work within their own organisation. Chapter Seven, Section 7.1 discusses and provides evidence of the influence of acts of institutional work.

What is the role of Hospice UK (the movement's membership organisation) in influencing hospices on the topic of dementia?

Hospice UK is a membership organisation and therefore in a functional sense have no formal role in influencing hospices on the topic of dementia. They function as a meta-organisation (Section 2.3) designed to act in the best interests of its members. This can be difficult if there are differing views from within the membership. It is clear from the evidence presented in Chapter Six, that there were clear perspectives from interview participants on the level of influence that may be deemed acceptable and that this also varied.

Hospice UK are often closer to government policy in terms of knowledge and influence, due to being able to represent the movement nationally in a way that over 200 independent organisations could not do. It could be argued that Hospice UK are in a better position to read the external environment at a national level and get a sense of any direction of travel by other legitimising organisations such as NHS England and the Care Quality Commission.

Hospice UK can influence via field configuring events (Section 3.4.1) and there is evidence they use this technique. In the context of dementia, there was the 2015 Hospice Enabled Dementia Care (Hospice UK, 2015) publication which was launched at a conference. Each year abstracts are requested by Hospice UK for their national conference. A panel select which abstracts are displayed as posters and which get presented. Hospice UK organise the conference inviting key note speakers etc. Hospice UK also publish e-newsletters where again they decide content. The conferences are wide and varied, however, they have the potential to influence, e.g. if keynote speakers are discussing dementia, heart failure, frailty for example it could be perceived that this is a method of legitimising certain activities.

The reality though is that whilst field configuring events can challenge and influence, ultimately any change is determined by individual hospices who are trying to balance their own vision with capacity, demand and financial sustainability.

How have hospices engaged with the dilemma of services for people with dementia and what are the associated barriers?

The survey data indicated that hospice's, almost unanimously (98%) believed that they had a role in supporting people with dementia.

However, based on the content analysis of the free text fields, there were differences of view in what this role might be. Of the 79 free text comments relating to the question of hospices role in the field of dementia, 30% (n = 24) considered

the issue of services for people with dementia as simply a matter of equality. However, 35% (n = 28) articulated a more selective response e.g. one of education, carer support or advance care planning. This lack of consensus continued in the interview data.

Hospices had engaged with the dilemma of providing services for people with dementia in a variety of ways. In commencing this engagement, 43% (n = 35) of hospices started with a strategic review focusing on local demographics and demand. Fairly equally, between 31% (n = 25) and 32% (n = 26) hospices had engaged via reviewing Hospice Enabled Dementia Care (Hospice UK, 2015), approaching partners or finding out what other hospices were doing. However, close behind that 27% (n = 22) of hospices had engaged in this dilemma because of an existing member of staff with a specific interest and therefore embracing disruptive acts of institutional work (Section 2.2.4).

Barriers were identified in the survey data and presented in Chapter Five, figures 5.1 to 5.8 (pages 147-152). 68% (n = 55), highlighted workforce skills and ability as a barrier followed by 54.9% citing build design and financial resource, with 54% (n = 45) being the impact of demand for existing services. These barriers very much focus on resources and are not unexpected. Despite having insufficient resources, hospices feel compelled to respond to the dilemma of services for people with dementia. Whilst workforce skills and abilities being a barrier was anticipated, evidence in the interviews, suggest that there is something more to understand about the extent to which the hospice workforce feel it is legitimate for them to care for people with dementia.

The fieldwork identified several pockets of activity where hospices had engaged in the dilemma of services for people with dementia. The data indicated two main categories of engagement, recognising it is possible to combine these:-

- Internal institutional entrepreneurship - this is when there is someone within the hospice with an interest who is able to use their knowledge, enthusiasm and commitment to influence change.
- Recruiting in expertise – there were two examples of this from within the focus group, one being the recruitment of an Admiral Nurse which is a post partly funded by Dementia UK providing support and raising the confidence of palliative care nurses within a hospice.

The qualitative fieldwork highlighted concern and confusion around models of care, identity and how to measure success. These institutional factors are key to moving forward in the debate about services for people with dementia and perhaps more widely for the movement.

8.2 Addressing research question two

This section will now discuss the response to question two.

Given this exploration of these organisational factors, what are the prospects for a (collective) response by hospices to the challenges posed by the demographic changes being faced?

This research would indicate that a collective response by the hospice movement is incredibly problematic. There is evidence of acceptance of the need for equal access to palliative care for people with dementia, although little consensus on what type of care is required and who should provide it.

Hospice UK, or a group of hospices, could drive a collective response to meet this challenge. The model by Greenwood et al. (2002) Figure 7.1 (page 198), provides a model of change that could be applied to hospices at an individual or movement level. Chapter Seven discusses how this model hasn't been completed by hospices collectively. The prevalence of dementia is a social 'jolt' (although not yet fully felt) as described by Greenwood et al. (2002) and there are examples of deinstitutionalisation and pre-institutionalisation such as the work by

internal institutional entrepreneurs within hospices and the emergence of Admiral Nurses working in partnership with hospices. However, as discussed in Chapter Seven, there is a gap in providing both technical viability and sufficient moral legitimacy to progress institutional change.

The historical narrative of hospice caring for people with cancer is still very dominant. If there needs to be an 'organisational failing' (Greenwood et al., 2002 p.60) in order for the process of institutional change to be fully embraced, this is a challenge for hospices. Arguably hospices have not failed in their original objective of meeting the needs of people with terminal cancer. Therefore, the key could be how to measure 'failure' from a different perspective of hospice narrative. In the fieldwork there were comments about the issues of equality of access, for some interviewees this was clearly a moral issue for them. The narrative for institutional change at field level needs to be constructed and applied consistently. Following the publication of Hospice Enabled Dementia Care (2015) there was an opportunity to follow a model of change such as Greenwood et al.'s (2002), however, this didn't happen.

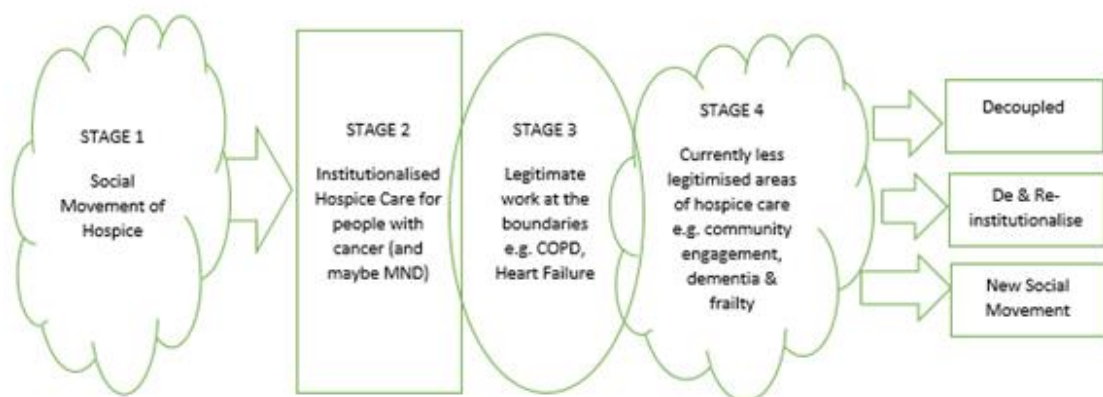
Greenwood et al. (2002) observed that in their research it was the use of more emotive language that supported the change. However, even if the narrative was compelling (which parts of Hospice Enabled Dementia Care (Hospice UK, 2015) was), hospices remain financially challenged. The technical viability that demonstrates a sustainable model of delivery is essential and missing from the national activities. Confidence is needed that new model maintains the social value of hospice within their community and enables a new narrative to be applied successfully. It is clear from the fieldwork that there is no consensus on a model of care for people with dementia across the hospice movement. Therefore, any technical viability must take place within the overall context of Greenwood et al.'s (2002) model.

54% (n 44) of survey respondents were concerned about the demand for services from the existing cohort of patients. Whilst there may be a moral compulsion to respond to this challenge barriers relating to financial and workforce resources mean there is little confidence in a sustainable change. There has not yet been sufficient evidence of a technically viable model of hospice care that meets the needs of people with dementia and balances organisational sustainability with a saleable solution at field level.

The empirical literature presented in Chapter Three, highlights that the challenges faced by other non-malignant disease categories are similar to those faced by people with dementia. The literature highlights the various challenges e.g. workforce capability, discussion relating to specialist and generalist palliative care, service models and prognostication.

Hodges and Read (2018)'s model, Figure 8.1 provides potential organisational outcomes in respect of dementia derived from this research for the hospice movement.

**Figure 8.1 - The evolution and current structure of hospice as an institution
(Hodges and Read, 2018)**



In the context of dementia it is theoretically possible for a collective response by the movement for service for people with dementia, however, the challenge of institutional change, the timescales involved and the resource constraints mean it

is highly unlikely that a solution of de and re institutionalisation will take place. If Greenwood et al.'s (2002) experience suggests a twenty-year timescale, then arguably the hospice movement is too late. The early calls for a response from palliative care for people with dementia from the NCPC in 2006 leading up to conferences like the one held in 2014 (see Chapter Three, Section 3.3.1) and David Cameron's 2012 Dementia Challenge had very little impact on hospices. There were some early services established e.g. Willow Wood Hospice, however, at field level and based on the evidence from NCPC on percentages of cancer patients accessing palliative care (Chapter One Section 1.2) there has not been a significant shift.

If de and re institutionalisation is not a likely outcome, then perhaps decoupling (Section 2.2.6) is a method by which hospices can contribute to the dementia agenda without attempting to shift the institutionalisation of 'stage two' in Figure 8.1. There is evidence of decoupling for example services supporting care homes. Decoupled services sit on the fringes of the institution of hospice and can therefore develop a new narrative.

Of course a new social movement may emerge externally to hospices, however, as things stand, care remains fragmented with a higher rate of hospital death for people with dementia in comparison to most of Europe. A new social movement could emerge from within the hospice movement, a 'splinter group'. This group, however, has to consider the risk of breaking out of the iron cage (Zietsma & McKnight, 2009) and the perception of legitimacy, equally those remaining 'in' also have to consider when to shift if the new splinter group gains traction and more importantly, legitimacy.

Whilst there are examples of hospices providing support for people with dementia, unfortunately at this point in time the prospects of a collective response by hospice seems unlikely. It is also unclear what change is desirable.

8.3 Limitations

This section will discuss the limitations of the study, some of these were known and anticipated at the beginning and others became apparent during the course of study.

- 1) Exclusions from the population – a key decision was which hospices to include in the population. It was easy to exclude children's hospices. However other categories excluded included NHS funded hospices and those part of national groups such as Marie Curie and Sue Ryder. The rationale was that decision making could be materially different to local charitable hospices due to whether decisions are made locally or nationally and how funding might be distributed. In hindsight it might have been useful to interview representatives from these excluded groups to understand whether there were difference in relation to organisational factors influencing decisions around services for people with dementia.

- 2) Survey follow up – potential survey participants were followed up three times. It is impossible to know whether additional contacts would have resulted in a higher number of returns. There were two limiting factors in relation to follow up firstly, time and resources, it was not possible to allocate the time to telephone individual hospices to chase up a response, secondly and more significant is the issue of not wanting to appear 'rude' when chasing people that are colleagues in other hospices, so whilst not knowing many of the target CEOs, it's a small world and three contacts seemed to be

professional and appropriate.

- 3) Focus Group – a limitation of the focus group is that it was via convenience sampling and therefore the target was an existing group. The first attempt at the focus group was to find a suitable date for people to attend a central venue, however only 4 participants from a list of over 80 were able to attend. Therefore a second attempt was made by tagging the focus group onto the end of a Dementia Community of Practice meeting. This was in London at the end of a day, so for some people travelling out of London staying for an extra session might have not been possible. However it is unlikely that the focus group could have taken place, not using this opportunity. The other limitation was that facilitating the discussion, knowing that the conversation was being recorded meant that individual voices were not noted, i.e. it is not possible to distinguish anything other than gender from the recording. This is not seen as a material problem in the focus group discussion, it is a collective conversation that is captured and it wasn't necessary to segment or identify individual voices.
- 4) Survey Results – the survey was not piloted. The pilot module within the doctorate focused on a different element of the study. In hindsight piloting the survey would have been helpful. The term n/a in some of the questions could be open to interpretation whereas it was meant to mean 'no plans'. The major limitation of the survey was not quantifying whether in stating that the hospice responding already offered services for people with dementia, the number of

patients this related to. As the numerical data is not available or reliable, the survey didn't ask for number of patients. However, an additional question could have been asked as to whether accepting referrals for patients with dementia (if the question was answered positively) was routine, occasional or rare.

- 5) Interviews – the interviews were part semi structured (i.e. the CEO participants and part unstructured (i.e. that national leaders). The limitations of this are that for semi-structured interviews, key information, which might emerge from an unstructured approach is missing. However equally in an unstructured interview, ensuring that the conversation is kept on track to both explore the breadth of a topic but also address key areas of inquiry is also a limitation. A certain degree of flexibility if required by the interviewer in order to balance these limitations of the method (Ritchie, et al., 2014).

8.4 Summary

This research provides hospices and other institutions with a theoretical and empirical narrative that can help understand and implement change. The institutional lens provides a range of concepts that help create a new language when exploring the 'jolts' that are faced for example legitimacy being a key term in considering how stakeholders may respond to change. The research provides models (Greenwood et al., 2002 and Hodges & Read, 2018) that can help frame discussions reflecting on previous change initiatives besides current and future challenges.

Institutional theory for this research was applied via the lens offered by Suddaby and Greenwood (2009) considering an interpretative and historical approach.

This combined with Selznick's (1957) old institutional theory centres the issues of

norms, values and cognitive understanding. The strong historical narrative of cancer and the application of 'specialisation' combines to institutionalise the distinctive identity of hospices. Whilst formed outside of the NHS there is a strong influence from healthcare professionals and regulators that creates this tension between old and new institutional theory. The community focus with key forms of cognition being values, norms and attitudes (Powell and DiMaggio, 1991, p13) in comparison with the 'field and sector' focus and concern about legitimacy.

There is a tension, evidenced in the fieldwork between the moral argument of equal access to hospice services, the historical narrative and the professionalisation of specialist palliative care.

Institutional Work Theory (Section 2.2.3) provides a level of analysis focused on individuals and their actions. This is useful to balancing the exploration of issues in relation to services for people with dementia at field, organisational, individual levels (figure 4.3, page 133). Acts of maintenance and disruption (Chapter Seven) demonstrate the lack of consensus exposed by this research.

Understanding 'why' certain acts of institutional work take place would be of interest in future research.

It is necessary to apply this tension to the resource challenges and the issue of technical viability of any proposed change. Until these tensions are fully explored and understood, it may limit any significant change.

This research aimed to explore the organisational factors influencing hospices' response to service for people with dementia. Whilst focusing on a particular group, the research can equally be applied to other patient groups not accessing hospice care or in fact any significant issues of change facing hospices. This qualitative exploration does not provide a solution but insight into why after fifty years hospice care has not significantly changed the population for whom it cares.

8.5 Recommendations

- 1) A national conversation – it is recommended that there be ‘field level’ discussion on the topic of dementia. Whilst this research is suggesting that a field level response is unlikely, although not impossible, with the right planning and momentum. However, the national conversation should be framed in a way that respects and understands organisational institutionalism. The conversation may need to start with hospices, however, should include communities, the NHS and other stakeholders. Clarity of a position on dementia would support a national change programme of some sort, if this is desirable.
- 2) Technical viability – it is recommended that there is a focus by Hospice UK and hospice boards on demonstrating the technical viability for areas of change, including dementia and that this becomes more standard in articles, conference proceedings etc. From a strategic perspective, the issue of technical viability (Greenwood et al., 2002) is a key concern, and appears to be absent from the national narrative creating ongoing confusion about appropriate models of care and providing confidence around business and financial modelling as a precursor to change. The NHS was created to provide universal health care, cradle to grave, free at the point of delivery. Hospice care was not.
- 3) Organisational institutionalism –training on institutional theory and change is recommended for within the hospice movement. Whilst many leaders may know about organisational change, there are specific challenges faced by hospices, institutional in nature – both old and new lenses of institutional theory. This development may help leaders plan and implement change programmes in a more effective way.
- 4) Dementia and identity – future research is recommended to understand the issues of hospice care for people with dementia and professional identity. This should include the extent to which specialist palliative care

practitioners consider it a legitimate use of their skills to care for people with dementia. The research highlighted some potential prejudices and/or stereotypes regarding care for people with dementia creating anxiety within the palliative care workforce.

- 5) Review of hospice's institutional change experiences – further research into institutional change within hospices would be of value to understand why, the movement hasn't shifted significantly beyond cancer.

Greenwood et al.'s study suggested that the use of emotive language was a key point of change. Discourse analysis (i.e. a study of written text) could explore how such language is being used in hospices, not just to raise voluntary income, but also to influence internal and external change. However, emotive language, without technical viability is unlikely to facilitate change.

This research aimed to explore the organisational factors that have influenced hospices' response to the dilemma of dementia. This thesis contributes new knowledge to the hospice movement, and more widely, in understanding what being institutionalised means and the challenges that this creates for change. It also supports hospices' understanding of the tensions between community-based charities and being part of an organisational field. However, it also fundamentally raises different questions to consider, for example:-

- What is considered as legitimate by different stakeholders when it comes to hospice care and what are the associated risks of testing 'legitimacy'?
- Does the future for hospice care require a different institutional narrative to the one it's had historically, and that still defines it today? If so how is that narrative created to provide a field level shift?
- How can Hospice UK provide confidence to members regarding the financial and resource risks related to field level institutional change?

This research was not designed to steer hospices regarding their response to the dilemma of hospice care for people with dementia. It aimed to explore the organisational factors behind the challenge. Its conclusion is therefore that the organisational factors when considered from an institutional perspective are significant. Without a clear understanding of institutional challenges combined with the resource constraints (that are more obvious), any field level change is unlikely if not impossible.

8.6 Final Reflections

It is hard to sum up my experience of completing this research. The learning curve was significant, however, when I found the right theory that combined my philosophical perspective with my professional knowledge, and applied it explicitly to this subject area things started to fall into place.

It has been illuminating being able to apply and study a theoretical lens to a particular issue. To discover brand new approaches such as organisational institutionalism and institutional work that add so much knowledge and reflection to hospice organisations. New concepts such as legitimacy and decoupling that provide insight and strategic options. Undertaking this study has added so much to my professional development and my ability to do my job.

As a Professional Doctorate student completing this research alongside the responsibilities of my CEO role has been incredibly useful. The theory and empirical data has helped me critically consider the strategic position and challenges of the hospice I work for. Despite looking at this research through an interpretative and historical institutional lens, and being convinced of the moral argument of improved end-of-life care for people with dementia, the resource challenge remains central. Starting out on this research I knew that the resource challenge would be a key issue identified in the survey, my interest was to explore what is underneath that i.e. the institutional narrative, the social context

and the views of hospice leaders why the issue of dementia has not created a shift within hospices. This research demonstrates why.

To de and re institutionalise would require such a momentous effort at field level and require a consensus across the movement. Even reflecting on my own hospice and my compassion for people dying with dementia, the issues of perceived legitimacy by the local community and therefore the sustainability of voluntary income and volunteering hours would concern me. In addition to the perspectives on legitimacy from the workforce. That said, as awareness of the deficits and inequity of care for people with dementia becomes more visible in society, there may be a compelling narrative that raises funds for a new type of hospice care.

Whilst I didn't see this research as providing a road map for hospice care with regards to dementia or to suggest that hospices should respond (despite my personal views), I am disappointed that the historical narrative is so strong, that institutional change remains difficult in the hospice context. Greenwood et al.'s (2002) model is incredibly useful and I hope that this and the development of my own institutional model (Hodges & Read, 2018) contributes something of tangible use to hospices.

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10 Appendix One – literature search

(see Chapter Three)

- a) Applicability of Palliative care for people with dementia
- b) Policy Literature
- c) Empirical Search Literature

10.1 Appendix 1A Policy Literature

Title	Author	Year	Search
National Service Framework for Older People	DOH	2001	DOH
Exploring Palliative Care for People with Dementia	NCPC	2006	Keele University Library
The Living Well in Later Life	Healthcare Commission et al	2006	Google
Progress with dementia: moving forward, addressing palliative care for people with dementia	NCPC	2007	Keele University Library
Dementia UK: The Full Report	Kings College London, London School of Economics & Alzheimer's Society	2007	Google
End of Life Care Strategy	DOH	2008	Researcher known
Creative partnerships: Improving quality of life at the end of life for people with dementia	NCPC	2008	Keele University Library

Out of the Shadows: end of life care for people with dementia	NCPC	2009	Keele University Library
The power of partnerships: palliative care in dementia	NCPC For Dementia and Alzheimer's Society	2009	Keele University Library
Living Well with Dementia: A National Dementia Strategy	DOH	2009	DOH
Counting the cost: caring for people with dementia on hospital wards	Alzheimer's Society	2009	Google
End of life care for people with dementia	Marie Curie	2009	Google
Quality outcomes for people with dementia: building on the work of the National Dementia Strategy	DOH	2010	Google
The Prime Minister's Dementia Challenge	DOH	2012	Google

Prime Ministers speech to the dementia 2012 conference	Cameron	2012	DOH
Dementia 2012: A national challenge	Alzheimer's Society	2012	Google
My Life until the End: Dying Well with Dementia	Alzheimer's Society	2012	Researcher known
Dementia State of the Nation	DOH	2013	Researcher known
Commission into the Future of Hospice Care	Hospice UK	2013	Researcher known
9 th Annual Conference on dementia and end of life	NCPC	2014	Google
Living and Dying with Dementia in England: Barriers to Care	Marie Curie and the Alzheimer's Society	2014	Researcher known
Prime Minister's challenge on dementia 2020	DOH and Social Care	2015	DOH
Hospice Enabled Dementia Care	Hospice UK	2015	Researcher known
Developing a non-cancer service: A resource for hospices	Help the Hospices	2017	Hospice UK

10.2 Appendix 1 B - Literature relating to the applicability of dementia

Name	Search	Type of Study	Yes/No	Comments
Chatterjee 2008	end of life care OR palliative care OR hospice + dementia or Alzheimer's	Evidence based article	No	it does comment on lack of access but doesn't substantially add to the discussion on applicability
Nazarko 2009	end of life care OR palliative care OR hospice + dementia or Alzheimer's	Evidence based article	Yes	mostly not relevant however does comment on disease trajectory being a barrier
Scott 2009	end of life care OR palliative care OR hospice + dementia or Alzheimer's	quantitative research	Yes	questions balance of specialist v generalist palliative care needs
Birch 2010	end of life care OR palliative care OR hospice + dementia or Alzheimer's	CPD evidence based article	No	it assumes applicability rather than adds to the discourse relevant to the thesis
Barber 2011	end of life care OR palliative care OR hospice + dementia or Alzheimer's	literature review	Yes	discusses specialist palliative care nurses and suggest most research on palliative care for people with dementia isn't from their perspective
De Vries 2011	end of life care OR palliative care OR hospice + dementia or Alzheimer's	case study audit	Yes	not relevant in demonstrating applicability, however useful re reliability of data for methods sections discusses a small audit in one setting so doesn't really add to wider debate either for this thesis

Name	Search	Type of Study	Yes/No	Comments
Sampson 2011	end of life care OR palliative care OR hospice + dementia or Alzheimer's	Evidence based article	Yes	questions relevance of hospices
Kelly 2012	dementia AND palliative care	editorial	No	short editorial, nothing to add to this discourse
Procter 2012	end of life care OR palliative care OR hospice + dementia or Alzheimer's	systematic review	No	doesn't relate to dementia and insufficient cross over discussion to include
Rowlands 2012	end of life care OR palliative care OR hospice + dementia or Alzheimer's	literature review	Yes	whilst references some of the same literature, add to the conclusions around lack of research and general understanding in this field
van der Steen 2013	dementia AND palliative care	delphi study	Yes	fundamental paper re applicability
Davies 2014	end of life care OR palliative care OR hospice + dementia or Alzheimer's	qualitative research	Yes	adds to this discussion re applicability and also that of organisational factors (added)
Torke 2014	dementia AND palliative care	Evidence based article	No	discusses three articles, only one of which is relevant to this study and that one is included in this list
Sleeman 2014	end of life care OR palliative care OR hospice + dementia or Alzheimer's	quantitative research	Yes	discusses wider issues re applicability
Dempsey 2015	end of life care OR palliative care OR hospice + dementia or Alzheimer's	Evidence based article	No	discussion paper based on available evidence already references so excluded.

Name	Search	Type of Study	Yes/No	Comments
McLaughlin 2015	dementia AND palliative care	Evidence based article	Yes	whilst also a general discussion paper this article references HUK 2015 publication and therefore included
Amador 2016	end of life care OR palliative care OR hospice + dementia or Alzheimer's	survey	Yes	Discusses development of services for people with dementia and references HUK 2015 publication
Harrison-Denning 2016	end of life care OR palliative care OR hospice + dementia or Alzheimer's	Evidence based article	Yes	discusses issues re policy and applicability of palliative care for people with dementia
Lillyman 2016	end of life care OR palliative care OR hospice + dementia or Alzheimer's	literature review	No	a general discussion paper based on available evidence much of which is already referenced in this list therefore excluded for that reason.
Etkind 2017	end of life care OR palliative care OR hospice + dementia or Alzheimer's	quantitative research	Yes	researches demand for palliative care including for people with dementia
Nyatanga 2017	end of life care OR palliative care OR hospice + dementia or Alzheimer's	Evidence based article	No	short editorial, nothing to add to this discourse
Fox 2018	end of life care OR palliative care OR hospice + dementia or Alzheimer's	qualitative research	Yes	the paper highlights gaps in the evidence and includes some research priorities

10.3 Appendix 1 C – Empirical Literature

Name	Search	Type of Study	Yes/No	Comments
Robbins 1996	Palliative care + service development	qualitative study	No	not relevant doesn't include issues relating organisational factors
Clark 1998	hospice + routinization	Thought piece	Yes	relevant as part of discussion on institutionalisation of hospice but not so re dementia or organisational factors
Field and Addington-Hall 1999	found from other bibliography	evidence based article	Yes	relevant as part of discussion on extending services for people without cancer - doesn't reference dementia or institutionalism
Johnson 1999	Hospice + movement	survey	Yes	has some relevance
Wiles 1999	Palliative care + service development	qualitative research	No	not relevant - doesn't add to discussion on either disease or hospice organisational factors
Humphreys 2001	hospice + institution	comparative study	Yes - historical	interesting as part of background history of hospice but not in terms of relevant research.
Shipley 2001	palliative care + institution	qualitative study	No	not relevant, change is referenced but not in any detail that adds to thesis discussion
Adams 2002	Palliative care + service development	Exploratory Case Study	No	Not relevant to this research, study was based in the NHS, it focused on a service innovation model and did not have any cross over into institutional theory or hospice

Name	Search	Type of Study	Yes/No	Comments
Tuffrey 2003	Palliative care + service development	literature review	No	not relevant it covers palliative care needs rather than access to and therefore doesn't add to the discussion
Payne 2004	hospice + organisation	cross sectional survey	No	doesn't add to the discussion and an old article re relevance
Addington Hall 2005	hospice + organisation	Survey	No	Not relevant to this research. Study explores views of hospice staff an volunteers. It doesn't follow up with interviews so doesn't explore participants rationale behind the survey results. It doesn't cross over to institutional theory or contribute to discussions on dementia. It is over ten years old therefore participants views are not necessarily comparable with todays.
Dunkley 2005	hospice + organisation	action research	No	not relevant, didn't reference organisational or institutional factors to add to the discussion
Payne 2006,	palliative care + professional identity	evidence based article	No	not relevant
Prail 2006	hospice + service development	article	No	not relevant
Jackson et al 2007	hospice + organisation	commentary	Yes - historical	not relevant - some useful historical background
Olthius 2007	hospice + professional identity	evidence based article	No	not relevant

Name	Search	Type of Study	Yes/No	Comments
Pooler 2007	hospice OR palliative care OR end of life care OR terminal care + change management	Thought piece	Yes	relevant
Selman 2007	hospice + service development / palliative care + service development	qualitative interview	Yes	has relevance in the fact is has little information re cultural issues
Monroe, 2008	hospice + service development	Thought piece	Yes	relevant in background and possibly some organisational issues
Jones 2010	hospice + organisation	grounded theory	Yes	possibly some relevance, i.e. breach of psychological contract with change
Brown 2011	Hospice + movement	social science theory based article	No	limited relevance, whilst touches on issues of legitimacy and institution it adds nothing to the research question itself, it's focus is on compassion and hope across both NHS and hospice.
Chambers 2012	hospice + organisation	Mixed methods	No	not relevant doesn't discuss any relevant factors re disease or institution
Anning 2013	hospice + bureaucracy	Thought piece	Yes	Builds on James & Field article re bureaucratization of hospice.
Morris 2013	hospice + organisation	Mixed methods	No	Questions relationship with the NHS and impact on hospice, marginal value to this research in adding to debate about where hospice is positioned between social movement and NHS.
Richfield 2013	end of life care + service development + dementia or alzheimers	article	No	not relevant, doesn't include issues re hospice/organisations

Name	Search	Type of Study	Yes/No	Comments
Charnock 2014	end of life care + service development / palliative care + service development	Thought piece	No	does not discuss organisational or institutional factors influencing care for people with heart failure
Davies 2014	end of life care OR palliative care OR hospice + dementia or Alzheimer's	qualitative research	Yes	adds to this discussion re applicability and also that of organisational factors (added)
Fisher 2014	hospice + Max Weber	qualitative research	No	not relevant, there are some interesting factors but not relevant to this study
Whittaker, 2014 Willis, Gannon et al 2014	hospice + organisational culture link from other article's references	qualitative research Thought piece	No Yes	not relevant whilst references organisational culture, it doesn't add on disease specific services or institutional factors relevant - heart failure
Arris et al 2015	hospice + organisational change / palliative care and organisational change / end of life care + organisational change	Mixed methods	No	study focuses on the method of study for the introduction of a new way of working. It doesn't reference institutional theory or discuss any issues relating to factors challenging existing ways of working.
van riat Papp et al 2015	palliative care + organisation + dementia or alzheimers	systematic review	No	not relevant doesn't add to organisational discussion
Amador 2016	end of life care + organisational change / end of life care + organisational change + dementia or alzheimers	Survey	Yes - Hospice applicability	relevant re discussion on dementia applicability but not institutionalism
Jones 2016	end of life care + organisation + dementia or alzheimers	Mixed methods	No	not relevant

Name	Search	Type of Study	Yes/No	Comments
Lillyman et al 2016	palliative care + organisation + dementia or alzheimers	literature review	Yes	should be relevant but isn't doesn't cover issue of hospice referral but worth referencing as per missing this angle
Becker 2017	end of life care + institution / palliative care + institution	Thought piece	Yes - policy	contributes to discussion on policy more than literature review i.e. not relevant research
Jansen et al, 2017	Hospice + organisation + dementia or alzheimers / end of life care + organisation + dementia or alzheimers	qualitative study	No	not relevant -doesn't add anything to this thesis
Lee 2017	end of life care + service development + dementia or alzheimers	qualitative study	Yes	relevant - adds to the discussion
Morris et al 2017		Mixed methods	Yes	possibly some relevance re volunteers and change
Payne 2017	hospice OR palliative care OR end of life care OR terminal care + change management / hospice + organisation	longitudinal case study	No	not relevant doesn't include issues relating to the institutional dynamics re integration
Siriyehh 2017	hospice + organisation	qualitative research	No	not relevant - not a similar topic and whilst different doesn't include institutional issues
Snowden, 2017	hospice + organisational change	Mixed methods	Yes	a different topic but includes some organisational issues that may be relevant
McCaughan, 2018	hospice + organisation	qualitative study	Yes	relevant as discussion includes hospice although is re a different patient group

11 Appendix Two – ethical approval

(see Chapter Four)

- a) Initial letter of approval
- b) Amendment to include a focus group
- c) Examples of....
 - i. Interview consent form
 - ii. Interview participant information
 - iii. Interview sample questions
 - iv. Focus group consent form
 - v. Focus group sample questions
 - vi. Focus group participant information
 - vii. Survey participant information
 - viii. Example survey

11.1 Ethical Approval



Ref: ERP1304

21st December 2016

Emma Hodges
Social Sciences
Keele University

Dear Emma,

Re: Taking an institutional work approach to explore how hospices are individually and collectively responding to the challenge of dementia

Thank you for submitting your revised application for review.

I am pleased to inform you that your application has been approved by the Ethics Review Panel. The following documents have been reviewed and approved by the panel as follows:

Document(s)	Version Number	Date
Interview Invitation Letter and Information Sheet	3	19-12-2016
Interview Consent Form and Consent for the use of quotes	3	19-12-2016
Interview Schedule	2	14-11-2016
Survey Invitation Letter and Information Sheet	3	19-12-2016
Survey Consent and Sample Questions	2	17-11-2016

If the fieldwork goes beyond the date stated in your application, **31st October 2018**, or there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator at research.erps@keele.ac.uk stating **ERP1** in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on research.erps@keele.ac.uk stating **ERP1** in the subject line of the e-mail.

Yours sincerely

Handwritten signature in blue ink that reads "C H Benneman". To the left of the signature, the letters "PP" are written in a smaller, lighter blue ink.

Dr Jackie Waterfield

Chair – Ethical Review Panel

CC RI Manager
Supervisor



Ref: ERP1304

22nd March 2017

Emma Hodges
Social Sciences
Keele University

Dear Emma,

Re: Taking an institutional work approach to explore how hospices are individually and collectively responding to the challenge of dementia

Thank you for submitting your application to amend study, informing us that a Focus Group has now been added to your research methods. I am pleased to inform you that your application has been approved by the Ethical Review Panel.

The following documents have been reviewed and approved by the Panel as follows:-

Document	Version	Date
Focus Group Invitation Letter/Participant Information Sheet	2	16-03-2017
Focus Group Consent Form and Consent for the use of quotes	1	08-03-2017
Areas for Focus Group Questions	1	08-03-2017

Just to remind you, if the fieldwork goes beyond the **31st October 2018**, or there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator at research.governance@keele.ac.uk stating **ERP1** in the subject line of the e-mail. This form is available via <http://www.keele.ac.uk/researchsupport/researchethics/>

If you have any queries, please do not hesitate to contact me via the ERP administrator on research.governance@keele.ac.uk stating **ERP1** in the subject line of the e-mail.

Yours sincerely

PP C H Bannerman

Dr Jackie Waterfield

Chair – Ethical Review Panel

CC RI Manager Supervisor

11.2 Examples of consent paperwork



11.2.1 Interview consent form

INTERVIEW CONSENT FORM

Title of Project: Exploring how hospices are individually and collectively responding to the challenge of dementia: A qualitative study.

**Name and contact details of Principal Investigator: Emma Hodges,
e.j.hodges@keele.ac.uk, telephone 07871705530**

Please initial box if you agree with the statement

1. I confirm that I have read and understood the information sheet dated
(version no) for the above study and have had the opportunity to ask
questions
2. I understand that my participation is voluntary and that I am free to withdraw at any
time, however that attributable quotes cannot be removed following publication.
3. I agree to take part in this study.
4. I agree to the interview being audio recorded
5. I agree to allow the dataset collected to be used for future research projects
6. I agree to be contacted about possible participation in future research
projects

Name of participant

Date

Signature

Researcher

Date

Signature



Title of Project: Exploring how hospices are individually and collectively responding to the challenge of dementia: A qualitative study.

Name and contact details of Principal Investigator: Emma Hodges,
e.j.hodges@keele.ac.uk

Please initial box if you agree with the statement

1. I agree for my quotes to be used and understand that attributable quotes cannot be removed following publication.

2. I do not agree for my quotes to be used

Name of participant Date Signature

Researcher Date Signature

11.2.2 Interview participant information

Interview invitation letter

Date

Exploring how hospices are individually and collectively responding to the challenge of dementia: A qualitative study.

Dear

I'm writing to invite you to take part in an interview as part of a research study in fulfillment of my DBA in Health Policy with Keele University.

My area of interest relates to hospices from an organisational perspective and the response to the challenge of dementia. I feel that, due to your professional experience you will have a valuable contribution to make to my research and I would love to hear your perspective.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. I have included this information in the attached participant information document.

Please take time to read this information carefully and do please contact me if you would like further information.

If you would like to participate, then please contact me on e.j.hodges@keele.ac.uk or on 07871705530 and I will then forward you the consent form for completion before arranging a place and time for us to meet.

Kind Regards

Emma Hodges
Post Graduate Student
Keele University

11.2.3 Interview sample questions

INTERVIEW SCHEDULE

Prior to the interview commencing

Remind the participant of key points from participant information sheet and consent including:-

- The interview will take approximately 1.5 hours
- To capture the interview accurately it will be audio recorded
- That the interview is anonymous and comments will not be attributed to them in the thesis unless they have consented for attributable quotes
- That the data will be used to address the research question and to understand how hospices respond collectively to drivers for change using dementia as a driver for change.
- That they can withdraw from the interview at any time and their data will not be used
- That they can withdraw at any time after the interview and if they do so any attributable quotes will be removed and that I will endeavour to remove anything specifically relating to their interview, however where data has been analysed i.e. informing general themes or conclusions this will not be possible.

Sample Questions

- What is your personal experience of the formation or development of an individual hospice?
- What is your personal experience of hospices as a movement?
- What are your views on the types of patients hospices care for and how that may or may not have changed over time?
- What are your views on factors that have challenged the hospice movement and caused either a greater connection or threatened to divide?
- What is your personal experience of changes within an individual hospice or the hospice movement?
- What are your views on the role of hospices when it comes to dementia and experience of any discussions they've been involved in locally or nationally?

11.2.4 Focus group consent form



FOCUS GROUP CONSENT FORM

Title of Project:

Exploring how hospices are individually and collectively responding to the challenge of dementia: A qualitative study.

Name and contact details of Principal Investigator: Emma Hodges, e.j.hodges@keele.ac.uk, telephone 07871705530

Please initial box if you agree with the statement

1. I confirm that I have read and understood the information sheet dated 16TH March (version no 2) for the above study and have had the opportunity to ask questions
2. I understand that my participation is voluntary and that I am free to withdraw at any time, however that attributable quotes cannot be removed following publication.
3. I agree to take part in this study.
4. I agree to the interview being audio recorded
5. I agree to allow the dataset collected to be used for future research projects
6. I agree to be contacted about possible participation in future research projects

Name of participant

Date

Signature

Researcher

Date

Signature

FOCUS GROUP CONSENT FORM

(for use of quotes)

Title of Project: Exploring how hospices are individually and collectively responding to the challenge of dementia: A qualitative study.

Name and contact details of Principal Investigator: Emma Hodges, e.j.hodges@keele.ac.uk

Please initial box if you agree with the statement

1. I agree for my quotes to be used and understand that attributable quotes cannot be removed following publication.

2. I do not agree for my quotes to be used

Name of participant

Date

Signature

Researcher

Date

Signature

11.2.5 Focus group sample questions

Focus Group Sample Areas to Question

Prior to the interview commencing

Remind the participant of key points from participant information sheet and consent including:-

- The focus group will take approximately 1.5 hours
- To capture the discussion accurately it will be audio recorded
- That the focus group is anonymous and comments will not be attributed to them unless they have consented for attributable quotes and in this case a pseudonym will be used.
- That the data will be used to address the research question and to understand how hospices respond collectively to drivers for change using dementia as a driver for change.
- That they can withdraw from the focus group at any time but their data will be used as it is difficult to distinguish their contribution from the rest of the discussion.

Sample Questions

- What has contributed to your interest in dementia care within hospices?
- What has been your experience of leading on the development of hospice services?
- Have there been any barriers to the development of hospice care for people with dementia
- If so are the barriers internal / external?
- What is your view on how people understand hospice care now?
- What are your concerns about dementia care for people with dementia?
- Has there been anything else that has challenged hospice care in this way?
- How have the Trustee Board been involved in determining a strategy for people with dementia?
- Have volunteers commented on this type of service development?

11.2.6 Focus group participant information



Information Sheet – FOCUS GROUP

Study Title: An exploratory study into factors influencing UK Hospice's policy on developing services for people with dementia?

Invitation

Thank you for showing an interest in taking part in this research study.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. Please take time to read this information carefully. Please ask me if there is anything that is unclear or if you would like more information.

Aims of the Research

The research aims to understand UK Hospices views and perspectives on developing hospice services for people with dementia and to identify some of the key influencing factors.

The research forms the thesis stage of my DBA in Health Policy.

Why have I been chosen?

You have been chosen as you are in a position in your professional role to contribute to addressing the research question.

Do I have to take part?

You are free to decide whether you wish to take part or not. If you do decide to take part you will be asked to sign two consent forms, one is for you to keep and the other is for our records. You are free to withdraw from this study at any time and without giving reasons.

The focus group data is not identifiable to you and therefore if you withdraw it would not be possible to withdraw any data you had contributed to the discussion.

What will happen if I take part?

You will be invited to participate in a focus group. The focus group will last about one hour.

Participation is not mandatory and names will not be disclosed during any part of the project other than to the other participants of the focus group.

If I take part, what do I have to do?

If you are willing to take part in the focus group you will be asked to discuss and write thoughts on flip charts that relate to the topic of developing hospice services for people with dementia.

What are the benefits of taking part?

You will be able to share your opinions and experiences with colleagues. The process may help you reflect on and influence your own hospice policy.

What are the risks of taking part?

This project is unlikely to carry any risks for its participants although it is not predictable what emotions may arise during the focus group discussion.

How will information about me be used and who will have access to it?

Information about you will not be published or used for any purpose other than for the researcher to contact you. A register of attendance will be taken at the Focus Group. The data from the focus group will be anonymous and therefore not attributable to any individual participant or organisation. The information about you will be kept for five years and stored securely on the Keele University computer network.

The information will only be accessible to myself and my two doctorate supervisors Professor Steve Cropper and Professor Sue Read from Keele University.

How will the data generated be used?

The data generated will be analysed and put into themes. The data will be used to address the research study title and possibly other research questions arising from the study.

All data will be stored securely on the Keele University computer network.

The researcher may use the data gathered in this study for future related topics in addition to possible articles and conference presentations

In the unlikely event that information shared indicates a breach of Care Quality Commission regulations or Safeguarding legislation, I would follow this up with you in private to discuss any required action i.e. notification to the relevant authorities.

How will the data be stored?

The flip charts from the focus group will be photographed and the data transcribed. The original flip charts will be kept until the thesis is completed.

The electronic documents will be imported into NVIVO a research software package. All electronic files will be stored on the Keele University computer network and be password protected.

Who is funding the research?

I am funding the doctorate myself.

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to me as the researcher on emma.hodges@stgileshospice.com or 01543 434540 and I will do my best to answer your questions. Alternatively, you may contact my supervisor for this study, Professor Calum Paton at Keele University, c.paton@keele.ac.uk.

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please write to Nicola Leighton who is the University's contact for complaints regarding research at the following address:-

Nicola Leighton

Research Governance Officer

Research & Enterprise Services

Dorothy Hodgkin Building

Keele University

ST5 5BG

E-mail: n.leighton@uso.keele.ac.uk

Tel: 01782 733306

11.2.7 Survey participant information

Survey invitation letter

Date

Exploring how hospices are individually and collectively responding to the challenge of dementia: A qualitative study.

I'm writing to invite you to complete a survey as part of a research study in fulfilment of my DBA in Health Policy with Keele University.

My area of interest relates to hospices from an organisational perspective and the response to the challenge of dementia. I would really appreciate your input into this topic.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. I have included this information in the attached participant information document.

Please take time to read this information carefully and do please contact me if you would like further information.

If you would like to participate, then please contact me on e.j.hodges@keele.ac.uk or on 07871705530 and I will then forward you the consent form and survey.

Kind Regards

Emma Hodges
Post Graduate Student
Keele University

11.2.8 Sample Survey

Name of Person Completing Survey

Role of Person Completing Survey

Name of Hospice

1. Was your hospice founded specifically to care for people with cancer or for a wider range of diseases?
 - a. Just cancer
 - b. Cancer and other diseases
 - c. Don't know

2. Does your Hospice provide hospice care for people with a primary or secondary diagnosis of dementia
 - a. Which services
 - i. Inpatient Services – primary / secondary / both
 - ii. Community Services – primary / secondary / both
 - iii. Day Hospice – primary / secondary / both
 - iv. Other – please describe

3. If YES to question 2, for how long has your hospice provided services for people with dementia?
 - i. 0-2 years
 - ii. 3-5 years
 - iii. 6 years plus

4. Does your hospice have a plan to increase access to services for people with dementia
 - a. Primary
 - b. Secondary
 - c. Both

5. What role do you think hospices have in supporting people with dementia at end of life?

6. What do you think are the key barriers to providing hospice services for people with dementia?
 - a. Functional issues such as financial resources, workforce confidence/competence
 - b. Capacity to deal with traditional hospice patients without expanding to a new group with different needs
 - c. A challenge to your philosophy / objectives as a hospice
 - d. Build design
 - e. Appropriate models of care
 - f. Other

7. In developing your response to hospice care for people with dementia has this started with
- a. A strategic review with a focus on external demographics locally
 - b. Hospice UK's Hospice Enabled Dementia Care Programme
 - c. A member of staff with a specific area of interest
 - d. Your personal experience with dementia
 - e. Other – please describe

12 Appendix Three – thematic map (see Chapter Four)

	Background					
	Background to starting services for people with dementia	changing demographics	external environment	Social Movement	visibility of dementia	
1 : Focus Group	0	2	1	0	2	
2 : Participant 1	0	2	14	0	2	
3 : Participant 10	0	2	2	0	0	
4 : Participant 11	3	3	4	0	2	
5 : Participant 2	0	2	1	1	5	
6 : Participant 3	0	1	2	0	4	
7 : Participant 4	0	9	6	0	0	
8 : Participant 5	0	0	1	0	3	
9 : Participant 6	1	0	1	0	2	
10 : Participant 7	1	2	3	0	2	
11 : Participant 8	0	1	5	1	0	
12 : Participant 9	0	1	1	0	2	

	equality	hospice similarity	Identity	moral obligation	Personal history	preconceptions of hospice
1 : Focus Group	1	0	0	0	4	0
2 : Participant 1	1	1	2	1	1	7
3 : Participant 10	0	0	1	0	4	2
4 : Participant 11	8	3	0	5	0	4
5 : Participant 2	0	1	1	1	1	5
6 : Participant 3	1	0	3	4	1	3
7 : Participant 4	4	1	0	3	2	4
8 : Participant 5	5	0	0	1	0	1
9 : Participant 6	2	6	1	0	0	1
10 : Participant 7	0	3	1	0	0	3
11 : Participant 8	2	0	3	2	2	6
12 : Participant 9	1	0	2	0	2	4

	Institutional Work		Organisations						Workforce				
	disrupting	maintaining	Boards	Hospice UK	Partnerships	strategy and decision making	Communication	Recruitment	role identity and value	specialist v generalist	Workforce confidence and capability		
1 : Focus Group	5	1	5	0	1	2	0	1	6	3	7		
2 : Participant 1	6	0	0	3	7	14	2	1	3	5	6		
3 : Participant 10	3	1	0	0	1	6	1	0	2	1	1		
4 : Participant 11	21	6	1	1	9	7	3	0	5	5	1		
5 : Participant 2	4	0	0	1	1	6	3	0	8	4	2		
6 : Participant 3	6	5	1	3	3	12	1	0	4	0	3		
7 : Participant 4	3	15	5	5	4	8	3	2	0	4	0		
8 : Participant 5	4	0	0	1	8	4	1	0	3	1	3		
9 : Participant 6	1	1	2	2	1	3	0	0	1	0	8		
10 : Participant 7	10	4	1	0	2	3	0	0	1	1	0		
11 : Participant 8	3	3	3	6	5	8	0	0	1	1	0		
12 : Participant 9	4	4	2	1	2	4	0	0	2	3	1		

	Services										Finance		
	care homes	education and training	Evidence base	new services or projects	policy & advocacy	referrals	service models	trajectory	Funding	statutory income	voluntary income		
1 : Focus Group	6	2	2	0	0	3	19	1	2	0	3		
2 : Participant 1	1	1	1	1	1	0	12	0	0	0	1		
3 : Participant 10	2	1	0	0	0	0	8	0	0	1	2		
4 : Participant 11	1	2	1	2	0	2	16	1	0	2	3		
5 : Participant 2	0	0	1	0	1	0	11	0	0	0	0		
6 : Participant 3	1	0	3	0	0	2	6	0	0	0	1		
7 : Participant 4	1	3	0	2	4	1	11	1	0	6	2		
8 : Participant 5	2	2	0	0	0	0	6	0	0	3	0		
9 : Participant 6	0	0	0	0	0	2	10	1	0	1	3		
10 : Participant 7	0	0	0	0	0	2	5	2	0	1	0		
11 : Participant 8	3	2	1	0	0	0	4	0	4	0	1		
12 : Participant 9	0	0	0	0	0	1	6	0	0	0	3		